

Understanding HIV Positive Patients' Perspective on Opt-Out, Incentivized, & Mandatory
HIV Testing

By
Sirena Sun
May 2009

A Community Based Master's Project presented to the faculty of Drexel University School
of Public Health in partial fulfillment of the Requirement for the Degree of Master of Public
Health

ACKNOWLEDGEMENTS

Special thanks to the Community-Based Masters' Project Faculty Chair, Dr. Nicole Vaughn, Community Site Preceptor Dr. Hans Schlecht, and the providers of Drexel University College of Medicine Partnership Comprehensive Care Clinic and Internal Medicine Clinic for their support and guidance throughout this research project process.

TABLE OF CONTENTS

Abstract	iv
Chapter 1: Background and Significance	1
1.1 The HIV/AIDS Epidemic in the United States	1
1.2 Centers for Disease Control HIV Testing Recommendations	1
1.3 Current Examples of Novel Testing Initiatives	5
1.4 Existing Literature on Patients' Perspectives on HIV Testing Models	6
1.5 Significance	8
Chapter 2: Specific Aims	9
Chapter 3: Methodology	11
3.1 Overview	11
3.2 Subjects	11
3.3 Data Collection	12
3.4 Data Analysis	13
3.5 Institutional Review Board Approval	14
Chapter 4: Results	14
4.1 Patient Demographics	14
4.2 Patients' HIV Testing Experiences and Opinions on Testing Initiatives	14
Chapter 5: Discussion	24
5.1 Opt-Out Testing	25
5.2 Incentivized Testing	25
5.3 Mandatory Testing	25
5.4 Lack of Awareness about HIV/AIDS	26
5.5 Patient Reactions to HIV Diagnosis	26
5.6 Limitations	28
Chapter 6: Conclusion	30
6.1 Future Research	30
6.2 Policy Recommendations	30
Bibliography	35
Appendix	39
Appendix A: Tables	39
Appendix B: Figures	41
Appendix C: Recruitment Flyer	43
Appendix D: Semi-Structured Interview Questions	44
Appendix E: Interview Transcriptions	45
Appendix F: IRB Consent Form	112

ABSTRACT

Understanding HIV Positive Patients' Perspectives on Opt-Out, Incentivized, and Mandatory HIV Testing

Sirena Sun

Faculty CBMP Chair: Nicole Vaughn, Ph.D.

Background: In the absence of a successful HIV vaccine, widespread HIV testing remains the best preventive action against further spread of the HIV epidemic. However, over 40% of the U.S. population has never been tested for HIV. To increase testing rates, in 2006 the CDC advised healthcare settings to conduct testing on an opt-out basis.

Objective: Qualitative, semi-structured interviews were conducted to address the lack of studies investigating patients' acceptance of and attitude towards this and more novel testing models, e.g. incentivized or anonymous mandatory testing.

Methods: Ten HIV-positive patients aged 18-64 were interviewed. Participants were asked about their HIV testing history and attitudes towards opt-out, incentivized, and mandatory anonymous HIV testing. Other ways to improve U.S. HIV testing rates were also explored. Major themes were identified using grounded theory data analysis.

Results: All participants were receptive to opt-out testing, and saw the removal of separate written consent as beneficial as long as patients were given the opportunity to consent in

some form. Participants still preferred providing counseling either before or after the test as a form of support. Participants were supportive of incentivized testing as a pragmatic measure to entice people to test, but felt that ideally these coercive measures shouldn't be needed to encourage individuals to look after their own health. Participants were supportive of mandatory testing with consideration for confidentiality of test results. Ultimately, both mandatory and opt-out testing were equally indicated by participants as being the most effective testing model at increasing testing rates. Some participants wanted testing to be mandatory but did not feel that it was a feasible testing initiative because it would never be implemented due to overwhelming resistance.

Conclusion: A firm understanding of patients' perspectives allows for development of effective HIV testing initiatives that are patient-sensitive and can substantially reduce HIV infection rates. Future testing initiatives must also be coupled with sufficient linkage to care and campaigns to increase awareness about the importance of HIV testing.

CHAPTER 1: BACKGROUND AND SIGNIFICANCE

1.1. The HIV/AIDS Epidemic in the United States

Currently over one million people are living with HIV/AIDS in the United States. Moreover, every 9 ½ minutes someone is infected with HIV (Kaiser Family Foundation, 2009a). Though advances in treatment have helped improve the quality of life for people living with HIV/AIDS (PLWHA) and prevent AIDS-related morbidity and mortality, the HIV/AIDS epidemic continues to be a significant public health problem. A recent report by the CDC indicated that 56,300 new HIV infections occurred in 2006, a number that was 40% higher than the previous CDC estimate of 40,000 infections per year (CDC, 2008).

1.2. Centers for Disease Control HIV Testing Recommendations

The importance of HIV testing as a method for preventing further spread of the disease has always been recognized and reflected in the CDC's recommendations throughout the HIV epidemic in the U.S. Routine voluntary counseling and testing (VCT) was first recommended by the CDC in 1987. At the time, testing was recommended for those considered high-risk groups: homosexual males, IV-drug users, hemophiliacs, sexual and/or needle-sharing partners of these individuals, and patients of sexually transmitted disease (STD) clinics. The recommendations also stressed the importance of counseling in helping uninfected individuals initiate and sustain health behaviors that reduce their risk for infection and helping infected individuals cope with their diagnoses and learn ways to avoid transmitting the disease to others (CDC, 1987). Over time, the CDC expanded its VCT

recommendations to include hospitalized patients and outpatients receiving care in acute-care settings (e.g. the emergency department) (CDC, 1993), and pregnant women (CDC, 1995).

In 2006, the CDC shifted from risk-based VCT to routine, opt-out testing. Under these new recommendations, all healthcare settings should screen all patients between the ages of 13 to 64 on a routine basis. Testing is no longer done based on presence of risk factors. In opt-out testing, patients are informed that they will be given an HIV test and consent is implied unless they specifically decline, or “opt-out” of the test. Moreover, separate written consent and pretest counseling requirements are no longer recommended. The updated testing recommendations for pregnant women include a second test for at-risk women during their third trimester of pregnancy, opt-out testing for women with undocumented HIV status during labor and delivery, and testing of newborns of mothers with unknown HIV status. Table 1 in Appendix A further outlines these testing recommendations.

These recommendations apply to all healthcare settings including inpatient services, emergency departments, and urgent care, STD, tuberculosis, public health, community, substance abuse, and corrections facility clinics. For healthcare settings with low or unknown HIV prevalence, universal screening should be conducted until the prevalence of HIV has been determined. If the prevalence is less than 0.001%, universal screening can be discontinued and other provisions can be made depending on the conditions of the healthcare setting.

1.2.1 Rationale for Updated HIV Testing Recommendations

The CDC changes in HIV testing recommendations were created to increase the number of people tested for HIV. It was determined that traditional risk-based testing was

becoming less effective at identifying undiagnosed HIV positive individuals due to the changing epidemiology of the HIV epidemic. Moreover, the existence of pretest requirements under VCT was seen as a barrier to testing. Written informed consent and pretest counseling requirements were removed to facilitate the testing process.

Originally, VCT testing was conducted based on the presence of risk factors: injection drug use, unprotected sex with men who have sex with men (MSM) or multiple partners, exchanging sex for money, and being diagnosed with or receiving treatment for tuberculosis (TB), hepatitis or STDs. However, these risk-based methods are no longer effective at identifying potentially undiagnosed HIV positive individuals. Though MSM do continue to be significantly affected by the disease (48% of new HIV infections in 2006), racial/ethnic minorities, women, and MSM subgroups are an increasing proportion of infected individuals; women account for 27% of new infections (CDC 2008).

Moreover, racial/ethnic minorities are disproportionately affected by HIV/AIDS (Figure 1, Appendix B). Though African-Americans only comprise 12% of the U.S. population, they comprise 45% of all new cases of HIV infections while whites consist of 66% of the U.S. population but only comprise 35% of new HIV infections (Kaiser Family Foundation, 2009a).

The CDC also recommended all healthcare settings to conduct routine testing to increase the yield of testing initiatives. Studies indicate that the healthcare settings in which people are most likely to get an HIV test are not the same settings in which they are most likely to receive a positive diagnosis. For example, most HIV tests (44%) are conducted in private healthcare settings, such as a primary care physician's office, but comprise only 17% of positive test results (Janssen, 2007). A greater proportion of positive test results are from

hospitals and emergency departments (ED) (27%) and community clinics (21%), while these settings only conduct 22% and 9% of tests, respectively (Janssen, 2007). These results indicate that most individuals receive HIV testing when they are seeking other healthcare services.

1.2.2 Current Implementation of CDC Recommendations

State laws remain a considerable obstacle to full compliance with CDC HIV testing recommendations. One of the key components of the CDC recommendations for routine, opt-out testing is the removal of separate written consent requirements. However, in the two years since the release of the CDC recommendations, nine states still have laws mandating separate written informed consent (Mahajan et al., 2009). Nine states allow for opt-out and general consent for medical care, three states do not specify opt-out consent mechanisms but allow for general consent for care to cover consent for HIV testing. Though these data indicate that most states are compliant with CDC recommendations, it is crucial that all states are conducting opt-out testing and their legislation does not impede implementation of opt-out testing initiatives.

1.3 Current Examples of Novel Testing Initiatives

1.3.1 Incentivized Testing

In addition to opt-out testing, alternative forms of HIV testing have been in use on a limited basis. Incentivized testing is a recent testing initiative where a small incentive (e.g. gift cards or movie tickets) is given upon completion of an HIV test in order to motivate

individuals to take the test. One study offered a \$25 incentive to patients who adhered with their emergency room referrals to outpatient HIV testing (Haukoos et al., 2005). The California Prevention and Education Project offers \$10 Safeway vouchers to individuals who complete an HIV test (Maher, 2008).

1.3.2 Mandatory Testing

Mandatory testing has also emerged as another alternative testing method for certain groups of individuals and situations such as pregnant women, federal prisoners, active duty personnel, and the testing of blood/organ donations (Kaiser Family Foundation, 2008b).

Currently, 17 states have legislation requiring mandatory HIV testing for pregnant women. If the mother refuses, her refusal will be noted and the newborn will automatically be tested. (Kaiser Family Foundation, 2008a). Exceptions are only made on religious grounds.

Several states also have implemented laws mandating testing of prisoners. For example, on February 2, 2007 the Texas Attorney General Greg Abbott ruled that state law allows the Texas prison system to mandate HIV testing for all inmates upon entry to any state prison unless they decline testing (Kaiser Daily HIV/AIDS Report, 2007a). Moreover, in September 2007, the Senate passed a bill (HR 1943) mandating HIV testing of all prisoners upon entry to and exit from any federal prison. Inmates would be allowed to opt-out of testing unless exposed to an HIV risk, such as pregnancy or a sexual encounter during incarceration (Kaiser Daily HIV/AIDS Report, 2007b).

1.4 Existing Literature on Patients' Perspectives on HIV Testing Models

1.4.1 Patients' Perspectives on Opt-Out Testing

Though these different types of testing initiatives have been implemented to limited degrees with the goal of increasing testing rates, few studies have investigated patients' perspectives on these testing initiatives. Haukoos et al. (2008) surveyed patients' opinion on opt-out testing in the ED of an urban safety-net public hospital. Over a three-month period, 529 patients were surveyed. 93% of patients would have agreed to take an HIV test if their physician had recommended it during their emergency room visit. However, it is important to make note that patients' responses were hypothetical because they were not actually offered an HIV test in this study.

Burrage et al. (2008) surveyed 30 women attending three urban community health clinics in Indianapolis on their opinions toward opt-out screening. The majority of respondents (80%) believed that opt-out testing was beneficial. However, seventeen (56.7%) participants felt that post-test counseling should not be eliminated. Corneli et al. (2008) examined the perspective of TB patients on three different types of routine provider-initiated HIV testing. The majority of participants were receptive to provider-initiated testing. However, because this study still maintained pre-test requirements, its results may not be applicable to opt-out testing that completely complies with the CDC's 2006 recommendations.

1.4.2. Patients' Perspectives on Incentivized Testing

Current available literature has not addressed patients' attitude towards incentivized testing. The available research examined the efficacy of incentives in encouraging particular

behaviors, such as following up on outpatient HIV testing referrals from the ED and encouraging adherence with HIV treatment regimens.

In one study conducted by Haukoos et al. (2005), 372 participants were provided outpatient HIV counseling and testing referrals. These participants were identified for testing based upon the VCT testing guidelines of the CDC. Testing referrals were done in three segments. In the first and third segment, no incentives were offered. In the second period, a \$25 incentive was offered for completion of the outpatient testing and counseling referral. During the two control periods, only a total of 8% of participants completed the testing referral while 23% of participants offered incentives completed counseling and testing.

Another study examined incentivizing treatment compliance for HIV-positive methadone patients who had a documented compliance rate of less than 80% (Barnett et al., 2009). Participants were randomized into either the control group receiving medication coaching or the intervention group where vouchers of increasing monetary value were provided for sustained treatment compliance. Adherence was measured by on-time opening of an electronically monitored medication vial. Perfect treatment compliance would result in the participant receiving a maximum of \$1172 in vouchers over the duration of the intervention. The intervention group had a compliance of 78% versus 56% in the control group.

1.4.3. Patients' Perspectives on Mandatory Testing

One study examined patient perspective on mandatory HIV testing. Simpson & Forsyth (2007) surveyed pregnant women and assessed their experiences with and opinion on Connecticut's state-mandated HIV testing. However, this study only examined one specific

case of mandatory HIV testing and the results may have limited applicability to other situations and individuals of differing demographics. Katz (2001) interviewed 32 pregnant women who had been offered prenatal screening in Canada. These women were asked about their own testing experiences, and their opinion on mandatory testing. However, the applicability of the study findings to U.S. settings is unknown.

1.5 Significance

Truly understanding patients' perspectives is the most effective way in creating fully informed testing initiatives that can effectively increase testing rates. Considering that the HIV/AIDS epidemic continues to be a substantial public health threat, all measures that can improve testing rates must be considered. The completed research is significant in that it provides unique insight on HIV testing, the patients' perception of the testing experience, and deficiencies in current and proposed testing initiatives. For example, the results of this research revealed a high degree of support for mandatory testing initiatives, which is often assumed to be a highly unfavorable and controversial testing option. Consequently, these results indicate that the public may be more receptive to more drastic changes than most health experts believed possible.

CHAPTER 2: SPECIFIC AIMS

Our long-term goal is to increase the rate of HIV testing and awareness of HIV serostatus in the Commonwealth of Pennsylvania. The objective of this community-based Master's thesis is to assess patients' responses to opt-out, incentivized, and anonymous mandatory testing to identify factors that would motivate individuals to be tested. The central hypothesis is that qualitative, semi-structured interviews of HIV positive patients will reveal that incentivized testing is the most appealing to patients. Previous research has shown that patients are receptive to physician-initiated HIV tests (i.e. opt-out tests). Thus, the addition of an incentive to test patients who do not engage the medical system may increase rates of HIV testing in the general public. The rationale for this proposed research is that successful identification of these factors will lead to fully informed recommendations and guidelines for HIV testing initiatives that can better increase testing rates, raise awareness of serostatus, influence future HIV testing initiatives and policy proposals and effectively contain further spread of infection.

We tested our central hypothesis and accomplished the objective of this application by assessing patients' responses in a semi-structured interview using open-ended questions to elicit elaborated responses. The following three specific aims were pursued:

1. Specific Aim 1: Assess HIV positive and negative patients' attitudes towards opt-out HIV testing.

The working hypothesis is that patients will be accepting of opt-out testing, as indicated in previous literature.

2. Specific Aim 2: Assess HIV positive and negative patients' attitudes towards incentivized HIV testing.

The working hypothesis is that patients will show a positive response to incentivized HIV testing.

3. Specific Aim 3: Assess HIV positive and negative patients' attitudes towards mandatory HIV testing.

The working hypothesis is that patients will show a negative response to anonymous mandatory HIV testing.

CHAPTER 3: METHODOLOGY

3.1 Overview

A qualitative study was conducted in which 10 HIV-positive men and women between the ages of 18 and 64 were interviewed using a semi-structured interview format. Participants were interviewed about their HIV testing history, their opinions towards opt-out, incentivized, and mandatory HIV testing, and what recommendations they had to improve testing rates in the U.S.

3.2 Subjects

A sample of 10 HIV-positive patients (8 male, 2 female) between the ages of 18 and 64 were recruited. Participants were currently receiving care from Drexel University College of Medicine's Partnership Comprehensive Care Clinic located in the Center City district of Philadelphia, Pennsylvania. HIV status was determined via patient self-reporting; participants were not required to provide documentation or obtain an HIV test to participate in the study. Criteria for inclusion were being between the ages of 18 and 64, reporting a positive HIV diagnosis, and being available to complete the 30-45 minute long interview. Criteria for exclusion were any medical condition which rendered the participant unable to complete the study, interfered with participation, or posed significant risk to the subject. Provisions were made in case of participants who do experience psychological and/or emotional distress in response to a particular question or topic. Participants were reassured that they could skip questions that they did not feel comfortable answering, and had the opportunity for referral to a counselor if they wished to alleviate their distress by speaking

with a mental health professional. Subjects were recruited through their physician to preserve patient anonymity. Physicians were approached and asked to broach the research topic with their patient and provide an informational flyer (Appendix C).

A total of 19 individuals were approached to participate in the study. Six individuals had declined to participate. Three individuals agreed to participate but were not interviewed because they did not return to complete the interview at the arranged date and time. Of these three individuals, two were lost to consent. These two subjects had completed the consent process and requested to return at a later date to conduct the interview. However, they did not return at the scheduled date and time for their interview.

3.3 Data Collection

Face to face interviews were conducted in a private room using a semi-structured interview format (Appendix D). All interviews were audio recorded. Questions were designed to illicit open-ended answers. Additional probing questions were utilized as needed to encourage participants to further elaborate or clarify their responses. Participants were asked questions regarding their HIV testing history, their opinions on opt-out, incentivized, and mandatory testing, and additional things that could be done to encourage individuals to obtain an HIV test. During the interview, subjects were referred to either by a nickname of their choosing or their subject identification number. Upon completion of the interview, participants were provided \$10 compensation for their time. The recorded interviews were transcribed verbatim (Appendix E).

3.4 Data Analysis

Interview transcripts were independently analyzed by the research team to identify major themes using grounded theory. Grounded theory is a qualitative data analysis technique that develops theory from the data rather than testing a preconceived theory via collected data (Glaser & Strauss, 1967). The main goal of grounded theory is to ultimately produce a theory that explains observed phenomenon (Glaser & Strauss, 1967). We chose to use grounded theory approach for data analysis to ensure that the resultant theory is as true to the data as possible and to avoid potential bias. Other methods of data analysis were not chosen because they are not as true to the data as grounded theory. Content analysis, another data analysis methodology, also employs coding to determine emergent themes. However, under content analysis data coding is mostly theory driven. Though content analysis can use emergent coding where the coding scheme is established based on preliminary analysis of the data, this method of data analysis may not be as faithful to the data and can be influenced by prior beliefs and ideas (Stemler, 2001).

The grounded theory approach to data analysis proceeds through four steps (Figure 2, Appendix B). The first step is open coding where the transcribed interviews are conceptualized for patterns or major events. A conceptual label, or “code,” is applied to the identified pattern or major event. All patterns and major events were grouped together by their codes. The second step was developing concepts that summarized the patterns identified in the transcripts. The third step was elevation of concepts into categories. During this step, concepts are grouped and classified into higher level, more abstract categories. The fourth step is development of major themes. During development of themes, the categories are refined and regrouped into over-arching themes that explain the linkages between categories.

Finally, a major theory is developed that explains why key relationships between themes exist and the meaning behind them.

3.5 Institutional Review Board Approval

This study was approved by Drexel University's Office of Regulatory Research Compliance. All subjects read and signed an informed consent form (Appendix F), which was kept in a locked filing cabinet in a locked office to ensure confidentiality and protection of participants' personally identifiable health information. All transcripts of the interviews were kept de-identified.

CHAPTER 4: RESULTS

4.1 Patient Demographics

Demographic characteristics of the participants are presented in Table 2 (Appendix A). The average age was 43.6 ± 7.32 years old, and the average length of time since they were diagnosed as HIV-positive to the present day was 11.3 ± 7.26 years. The average length of time from diagnosis to initiation of treatment was 9.27 years, with a range from 1 month to 15 years. All participants were currently receiving care at the Drexel University College of Medicine Partnership Comprehensive Care Clinic.

4.2. Patients' HIV Testing Experiences and Opinions on Testing Initiatives

Analysis of the interviews yielded seven major themes, which are discussed below. Patients described the circumstances surrounding their HIV test, what motivated them to get

tested, their testing experience, their reactions to their test results, their opinions on the HIV testing models (opt-out, incentivized, and mandatory testing), and which model they felt would be best to increase testing rates.

4.2.1 Testing Factors

The first theme identified was testing factors. These are modifying factors that influence an individual's decision to get tested. There were two categories of factors, intrinsic and extrinsic, that affected participants' testing behaviors.

Half of the participants were first tested for HIV due to intrinsic factors. Participants described concern over physical health (either prompted by an illness or a desire to prevent disease contraction and transmission) as their reason for testing. For instance, "I was feeling sick, I wasn't feeling so well so I went to the doctor to find out what was wrong," or "It was more to see if I was okay, but I just didn't want to pass anything along to anybody."

Other participants discussed perceiving oneself to already be at risk for contracting the disease as their reason for getting tested. "One time I really took a test because I was sick. And uh I knew that in my mind I was being destructive and doing destructive behaviors, sexual behaviors, not protecting myself." Another participant stated, "Um when I first got tested I was kind of nervous because I knew that I may have the disease and I was kind of scared."

The other half of the participants were first tested for HIV due to extrinsic factors, meaning they did not proactively request an HIV test but instead were in a situation where HIV testing was being performed. One participant received testing through blood donation. Others were tested either as part of procedure during incarceration, or participation in a

research study. Another participant was tested due to hospitalization, but could not remember if he had consented to take the test.

4.2.2 Reactions to Test Results

The second theme was one of negative defense mechanisms in response to participants' HIV positive test results. These defense mechanisms consist of emotional reactions and utilization of coping mechanisms. All participants expressed negative emotional reactions to diagnosis. Participants expressed feelings of depression, and viewing their positive diagnosis as a death sentence. One individual described, "I felt like that was the end of my life," "It was like the end of something." Two participants expressed feelings of isolation, with one exclaiming "you feel....like a leper," and the other explaining that "I feel as though, I don't know, that there's not a person out there for me now." Four participants described negative coping mechanisms. These coping mechanisms consisted of denial about positive test result and refusal to come to terms with the diagnosis. One participant stated "I just medicated myself through the whole thing," and another described that they felt that "there ain't nothing wrong with me." Two participants coped by distracting themselves through involvement in other activities. One explained that she "just buried [herself] in programs in getting people how to you know, be safe, encouraging people to get tested." The other participant stated that he "just kept [himself] busy with the prison program."

4.2.3 Testing Experiences

The third theme was testing experiences. Testing experience were events that participants encountered when they were first tested for HIV, such as experiencing testing

difficulties, and receiving pretest counseling. Participants explained that they had experienced difficulty in getting tested due to stigmatization. One participant captured this feeling of shame when he explained “you wanted to have a coat over your head because you didn't want nobody to know.”

Half of the participants (n=5) did not receive pretest counseling. Four participants did receive pretest counseling. One participant could not remember if he received pretest counseling because as described, “everything was so overwhelming to me that if they did do that with me, I didn’t...I wasn’t... it just went in one ear and out the other.”

Though many of the participants did not receive pretest counseling, all participants expressed the need to continue to have counseling at some point during the testing process. One participant explained that counseling was needed because the people being tested “need to know that it’s not going to be the end of the world.” Others expressed that counseling was important so that individuals will know and understand the implications of testing positive, and that counseling is needed as a source of support and comfort.

4.2.4 Opt-Out Testing Seen as Beneficial

The fourth theme was opt-out testing seen as beneficial. All participants were receptive to opt-out testing and felt that this testing model would help encourage people to test. Their positive responses to opt-out testing centered on the idea that any method that would streamline the testing process would help increase the number of people tested for HIV. For example, one participant remarked about testing that “anything that makes it easier and more accessible is going to be helpful.” Another participant explained that opt-out testing is beneficial because “it’s much quicker where you won’t have so much on your mind.”

Moreover, making HIV testing as part of a routine physical was also appealing. One participant stated “Yeah, I think I prefer this, just to make it normal routine to encourage people to do it every, just you go normally... like dental you have to go every 6 months.”

It was interesting to note that one participant cautioned that though opt-out testing is beneficial because it makes the testing process easier, the individuals who do refuse to take the HIV test may be problematic. This participant explained that “my first thought is anyone that would opt-out of...not wanting to be tested for HIV is someone that needs to be tested for HIV.” He further stated that “if someone opts out it should be mandatory at that point that they get tested.” Meaning, the individuals who refuse to take an HIV test are the ones who are at risk, could potentially already be infected, and need to be tested but do not want to deal with the implications of an HIV positive diagnosis.

When participants were questioned about specific provisions of opt-out testing (e.g. removal of separate written informed consent requirement), all participants felt that removing paperwork would help increase the testing rates. Removal of paperwork would be beneficial because, as one participant described it, “that paperwork is aggravating, frustrating” and that “all that paperwork really will make a person not want to be involved with it.” Participants felt that verbal consent is sufficient. As long as a patient is given the opportunity to consent in some way, participants found removal of written informed consent acceptable.

4.2.5 Testing Barriers

The fifth theme was testing barriers. Participants’ responses regarding testing barriers fell into two general categories: the need for absolution of responsibility and lack of knowledge about HIV. Participants stated that individuals may not get tested for HIV

because they are afraid of the consequences of a positive HIV test result and do not want to have to deal with those implications. A participant stated that “there’s a reason why they’re not aware. They don’t want to be aware as long as they feel okay, they’re not going to say anything because of the stigma.” Moreover, by not testing people do not have to cope with changing their lifestyle according to their serostatus. One participant explained that “being negative you get a lot more action.” Another participant touched on the criminalization of HIV transmission. He stated:

“Say I have sex with a girl. And I don’t know I have AIDS and I give it to her, right. Can I still be charged with attempted murder? No, right? I have to know I have it. So see that right there is a deterrence for some people.”

Another reason that people do not get tested is because of a lack of knowledge about the disease, and fear of the disease that stems from this lack of knowledge. One participant stated that “You gotta be closer to a cure for people to want to get tested. And, and have people realize that it's not a death sentence. You can live with it.” People are also afraid to get tested because of the severe stigma that still exists surrounding the disease and the ostracization of HIV positive individuals due to the lack of knowledge about the disease in the general public. One participant stated that “these groups look down significantly on [HIV] positive people and they’re looked at as dirty and unclean.”

4.2.6 Incentivized Testing

The sixth theme was participants' opinion on incentivized testing. Participants' responses to incentivized testing fell into two categories of pragmatism and idealism. Some participants felt that incentivized testing will work in motivating people to test because, as one participant put it, "I think it's an attraction to get your information across." Participants explained that the reason why incentives work is because a person would be willing to take a test as long as they are "getting something in return." Participants felt that incentives would help individuals go through with testing out of the desire to get the incentive. One participant exclaimed that "it would spark my interest enough to go ahead and see about my health."

However, participants also recognized that it was "a shame to have to pay people to be proactive and concerned about their own health." One exclaimed, "why pay me to go take a test? It's for my health, it's for my benefit." Another stated that "it shouldn't be necessary for people to be paid to find out if they have HIV or AIDS because it's your life." Participants also stated that testing for HIV ideally should be free of coercion, and participants recognized that incentivized testing was still a form of coercion. One participant framed the incentive as "taking a bribe. Somebody bribe me. If you do this I'll give you that, okay." Participants also noted that if incentivized testing is going to be used, incentives should only be a small amount of money, about \$5 to \$10. It was stressed to "go the most inexpensive way" to avoid coercion. Also, one participant expressed concern that incentivized testing would not be effective because it would not encourage individuals with high risk behaviors. He stated "you'll probably get a bunch of people who don't have it that just want the money, and ain't worried about their rep because they're negative."

4.2.7 Types of Incentives

When participants were questioned about what type of incentives would be best to give to people, their responses fell into two categories: entertainment-type incentives and incentives for basic necessities. Entertainment-type incentives included movie tickets and basketball tickets while incentives for basic necessities included free health exams, and money or vouchers for food or groceries.

4.2.8 Opinion on Mandatory Testing

The seventh theme was participants' opinions on mandatory testing. Participants were asked their opinion regarding this type of testing, and Connecticut's legislation requiring all pregnant women to be tested for HIV was discussed. Their responses fell into one of two categories: support for mandatory testing due to the need for desperate measures to contain the epidemic and the need to respect autonomy. One participant's response captured the feeling that drastic measures would be required to curb the HIV epidemic. He exclaimed "it's got to become a mandatory test. You want to end it? Make it a mandatory test." Another participant echoed the importance of getting tested when he explained "people need to know if they're HIV positive or negative because it's an epidemic." Others described the need to get people to test for their health and the health of others. For example, "It's nothing to be ashamed of, it's just a health, just to find out. It's our life, it's my life, so I think it's important." Another participant stated:

“if you’re not going to do what you need to for yourself, like get tested, then you should...it should be mandatory to get tested to make sure that one you’re okay for your own self but as a protection to the other people around.”

Some participants were supportive of mandatory HIV testing under certain conditions. For example, “That should be mandatory for pregnant women because why give birth to a child that’s going to live with HIV? You know, that’s like...it’s not fair to the child. It’s not,” or “They should be mandatory when you go to prison, and if you’re going to rehab. If you’re on any kind of government assistance.” Mandatory testing was also acceptable with consideration for confidentiality of test results. For example, one participant explained that he had no problem with mandatory testing “as long as it’s confidential.”

There were participants who were against mandatory testing because they felt that it violated patient autonomy. They felt that mandatory testing was “interfering with someone’s rights.” One participant stated, “It’s their choice if they want to get tested or not. You know, do I agree with it? No. No, but it’s their choice.”

4.2.9 Mandatory Testing Examples

Participants were asked to generate examples of mandatory testing that they felt would work. Their responses fell into one of two categories: 1) mandatory testing in health settings or 2) in government settings. Participants exclaimed that mandatory testing should be done as part of an annual physical, or mandate that all individuals who enter the hospital should be tested for HIV. Government settings for mandatory testing were linking HIV

testing to drivers' license renewals, filing tax returns, incarceration in local and federal prisons, and job interviews.

4.2.10 Most Effective Testing Model

Out of all three testing models that participants were interviewed for their opinions, both mandatory testing and opt-out testing were indicated as the most effective in getting people to test for HIV. Three out of the ten participants indicated mandatory testing as most effective over the other two testing models. Three participants named opt-out testing the most effective. Two participants claimed incentivized as the most effective. One participant did not have a clear indication of opt-out or incentivized being more effective than the other, but he did not agree with mandatory testing. One participant stated liking both opt-out and incentivized equally, and preferred mandatory testing as long as test results were confidential but felt that it would not be possible to implement it.

It is important to take note that of the three participants who selected opt-out testing as most effective, two participants felt that testing should be mandatory, but did not select mandatory as the most effective testing model because they felt that it would never be implemented due to overwhelming resistance from the general public to such a mandate.

4.2.11 Participant-Generated Alternatives to Increase Testing Rates

When participants were asked to generate other alternatives to increase testing rates, their responses fell into two categories: increase testing rates via active or passive recruitment. Active recruitment involve events that are proactively reaching out to the community to raise awareness about the importance of HIV testing and HIV testing

locations. This type of recruitment involves more direct person-to-person contact.

Participants listed conducting community events such as health fairs, conducting testing follow-ups, conducting testing at bars, and performing community-based projects.

Passive recruitment involves methods that provide information to a widespread audience and do not involve direct contact with individuals to increase awareness about testing and testing locations. Participants listed posting advertisements at bus stops or on billboards, airing public service announcements on radio or TV media, and placing postcards in the mail.

CHAPTER 5: DISCUSSION

This study identified both mandatory and opt-out testing as the model that participants identified as the best model to improve testing rates. An equal number of participants chose mandatory as opt-out. Participants who felt that mandatory testing was best was because of the severity of the HIV epidemic and the need for desperate measures to curb the spread of the disease. Participants also emphasized that it was extremely important for individuals to know their HIV status because they believed that it was individuals' lack of awareness about their status that increases transmission of this disease. Participants felt that the major reason individuals did not test was because they did not want to cope with the implications of a positive test result and the potential social isolation due to the stigma associated with HIV positive individuals.

5.1 Opt-Out Testing

The findings of this study regarding patient's attitudes towards opt-out testing are in agreement with existing studies that indicate that patients are receptive towards physician-initiated HIV testing (Haukoos et al., 2008; Burrage et al., 2008; Corneli et al., 2008). Patients are in general trusting of their doctors and most comply with physician-recommended actions.

Participants also felt that removal of separate written informed consent would ease the testing process and encourage more people to test, which is in agreement with the findings of Zetola et al. (2008), and the initial intent of the CDC when these updated testing recommendations were created. In Zetola et al.'s study, the average monthly rate of HIV tests per 1000 patients increased by 44%, and the monthly average number of new HIV positive test results increased by 67% with the removal of the separate written informed consent.

5.2 Incentivized Testing

Though there is no research on patients' perspectives on incentivized testing, the finding that participants were amenable to incentivized testing parallels the success of using incentives to encourage compliance with outpatient testing referrals.

5.3 Mandatory Testing

The degree to which patients were supportive of mandatory testing was unexpected. The high number of participants choosing mandatory testing indicates that these participants recognize the urgency of the HIV epidemic situation and the importance of serostatus awareness, and the subsequent need for more HIV testing. Their acceptance of mandatory

testing may also be influenced by their positive diagnosis. Familiarity with the disease and the severity of its effect on a person's health may have caused some participants to be more amenable to more aggressive means of increasing testing rates.

5.4 Lack of Awareness about HIV/AIDS

Many participants emphasized that there is limited awareness of HIV/AIDS currently compared to when they were first tested for the disease. All participants indicated some form of education campaign when asked for alternative methods to increase testing rates. Their observations were reflected in a recent nationwide Kaiser Family Foundation survey (2009b). The results of this survey indicated that the percent of individuals who had personally seen, heard, or read about the problems of AIDS in the U.S. had fallen from 34% in 2005 to 14% in 2009. Moreover, the percent of individuals who had "heard nothing at all" about AIDS increased from 4% to 12%. Those who had heard only a little increased by 18% from 25% in 2004 to 42% in 2009. Interestingly, health officials recognized this increasing sense of complacency and the White House, HHS, and CDC recently launched a five-year HIV/AIDS awareness campaign titled "Act Against AIDS." The goal of this initiative is to educate the public that every nine and a half minutes someone is infected with HIV and also provide information on testing locations and resources (Kaiser Daily HIV/AIDS Report, 2009).

5.5 Patient Reactions to HIV Diagnosis

All patients had negative emotional reactions to their HIV positive diagnosis. Patients described that they were in shock, and many described being in denial and not coming to terms with their diagnosis. It is interesting to note the length of time between patients' receipt

of a positive HIV diagnosis and initiation of treatment. The length of time ranged from as little as 1 month to as long as 15 years, with the average length of time being 9.27 years.

These patients' reactions to their diagnosis are similar to the Kubler-Ross model (1969) of the process by which individuals deal with grief and tragedy by progressing through five stages: denial, anger, bargaining, depression, and acceptance. According to Kubler-Ross, patients will let go of their denial and use less radical defense mechanisms depending on how patients were told about their diagnosis, how much time patients have to acknowledge their illness or situation, and how their life experiences have prepared them to cope with stressful situations.

A considerable proportion of study participants were from low socioeconomic backgrounds; 40% of these participants had at most attained a high school education. Moreover, the majority of patients did not receive pretest counseling or any form of counseling, and had received their test results in a direct manner partially due to the conditions in which they were tested. These factors may have contributed to the long length of time between diagnosis and treatment because participants were not equipped with healthy coping mechanisms based on previous life experiences. In addition, the fact that HIV can remain dormant without any noticeable or severe effects on an individual's health could also contribute to the difficulty with which participants may have had in coping with their diagnosis and seeking treatment.

The severe social stigma and resultant fear and isolation towards HIV positive individuals may also have impeded these participants' health-seeking behaviors. Most participants were first tested for HIV during the late 1980's and early 1990's. During that time period, the epidemic was still relatively new, many people were misinformed about the

disease and how it is transmitted, and stigma against the disease was much higher back then than it is today. The overwhelmingly negative public attitude towards HIV/AIDS may also have contributed to participants' aversion to seeking treatment and coming to terms with their diagnosis.

5.6 Limitations

The small sample size and the demographics of the sample place limitations on the generalizability of these findings to other settings. The majority of participants were African-American males who had at most a high school education, annual family incomes of less than \$20,000, were unemployed and were publicly insured. Moreover, participants were all HIV positive. Their familiarity with and acceptance of the disease may have skewed their responses in favor of more drastic testing methods because they have first-hand experience with the severity of the disease. Self-selection of participants may also have biased the sample. Meaning, participants who had strong feelings regarding HIV testing that might not be representative of the general population or of the HIV positive population were more likely to volunteer to participate in the study than others who are more ambivalent towards HIV testing.

Moreover, only HIV positive patients' perspectives were included in this report. The original research proposal did include HIV negative patients, and data were collected for this population. However, due to time constraints their data were not included in this report.

Recall bias, which is subjects' misremembering some facts, and social desirability bias, which is the subjects' desire to not be viewed negatively by the interviewer, may also have skewed the findings. Participants may have censored some of their responses or

responded in the way that they believed is “socially acceptable.” For example, some participants had initially stated that they believed mandatory testing was fair, but upon further probing had changed their mind and stated that they did not believe it was fair and that it interfered with an individual’s right to choice. Thus, the participant may have felt that it was wrong to believe that it was acceptable to encroach on an individual’s civil liberties for the sake of increasing HIV testing rates and either expressed discreet support for mandatory testing or decided to not express their support at all. Some participants also either did not fully understand the questions that were asked or misinterpreted them, and the interviewer did not catch that they had misinterpreted the question or did not fully answer the question until after the interview had concluded.

Interviewer bias, as to the manner in which the interviewer phrased the question or the interviewer’s tone of voice, may also have consciously or subconsciously influenced the participant’s responses. For example, the interviewer had asked participants if they thought mandatory testing was fair. This phrasing of the question may have led participants to believe that they were not supposed to answer that mandatory testing was fair. Interviewer bias can be addressed through usage of computerized interviews. The benefit of this type of interview is that it allows for uniform phrasing and presentation of questions and does not let verbal or nonverbal cues from the interviewer to influence responses (Bachman, 2003). Moreover, patients may feel more comfortable when answering controversial questions and thus be more likely to provide answers closer to their true beliefs and attitudes. However, computerized interviews cannot detect nonverbal responses such as body language that may offer additional information about their responses.

CHAPTER 6: CONCLUSION

6.1 Future Research

Considering the small sample size and limited generalizability of these findings, future research should be conducted with larger sample sizes that also include HIV negative populations, and individuals from a wider range of socioeconomic and racial/ethnic backgrounds. Other healthcare settings should also be included considering that the characteristics of patients receiving care from, for example, private physician office settings, will be different from those of clinics in academic settings.

Future research directions may also investigate patients' perspectives on criminalization of HIV transmission and its effect on HIV testing behaviors. Criminalization of HIV transmission has been a recent development in the news media. For example, a man in Iowa was recently sentenced to 25 years in prison for not disclosing his HIV status and knowingly transmitting the disease to another individual (Stegmeir, 2009). Moreover, this man was required to register as a sex offender and undergo a sex offender treatment program, and was also given a five-year no contact order with the victim. The significant penalties associated with knowingly transmitting HIV may have a negative impact on HIV testing because individuals may become unwilling to test due to the implications associated with serostatus awareness.

6.2 Policy Recommendations

This study has important clinical and public health policy implications. Considering that all participants are supportive of opt-out testing and not many were opposed to

mandatory testing, a good first step to bolster current CDC opt-out testing recommendations would be to mandate that all physicians must test their patients at their annual physicals, and all emergency room admissions must be screened on an opt-out basis.

6.2.1. Addressing HIV/AIDS Complacency

It is also crucial to address the increasing sense of complacency in the U.S. regarding HIV/AIDS. Many are not as aware about HIV/AIDS and do not believe that it is a significant health problem anymore. In a recent survey conducted by the Kaiser Family Foundation (2009), the percentage of Americans who named HIV as the most urgent health problem facing the nation decreased from 44% in 1995 to 6% in 2009 (Figure 3, Appendix B). However, recent studies by the CDC (2008) indicated that the annual rate of new HIV infections in the U.S. were over 40% higher than previously estimated.

This discordance between increasing infection rates and increasing complacency about the disease will only exacerbate the epidemic unless the problem is addressed. The recently launched campaign by the White House, HHS, and CDC is a good first step to combat low awareness. Hopefully the five-year program will result in increased testing rates. However, it is important to emphasize that awareness campaigns must not be cyclical and reactive. In order to contain the current HIV/AIDS epidemic, awareness campaigns must be constant so that individuals are always receiving information about the severity of the disease. One important barrier to testing that participants had described was the idea that many people believe that they are not at risk, that because they “feel fine” they do not need to be tested. Another is stigma. However, awareness campaigns will help in combating these barriers by educating the public that HIV is similar to other chronic health conditions. With

the advent of new medical and pharmaceutical advances, the disease is no longer a death sentence.

6.2.2. Ensuring Adequate Financing of Routine HIV Screening

Though the CDC has recommended that all healthcare settings conduct routine opt-out testing and several states have legislation that facilitate opt-out testing, the issue of financing expanded HIV testing may also complicate the ability of healthcare facilities to comply with these recommendations. A recent review conducted by Burke et al. (2007) indicated that inadequate reimbursement was one barrier that physicians had indicated as a barrier to offering HIV tests to their patients.

A potential method to address reimbursement issues is to advocate for amendment of the federal Employee Retirement Income Security Act of 1974 (ERISA) to include HIV testing as one of the benefits covered by ERISA plans. ERISA is a federal statute that stipulates minimum standards for all employee pensions, health, and other benefits plans that are offered by private-sector employers or unions (National Academy for State Health Policy, 2000). Unfortunately, amendment of ERISA would not benefit uninsured or self-insured individuals.

Another method would be to advocate for states to pass a bill in similar fashion to California that requires all health service plans and insurers to cover HIV testing. In October 2008, California signed into law AB 1894 that mandated that all health service plans and insurers cover HIV testing (Cathcart, 2008). Under this bill HIV testing also becomes a covered service under the California Medicaid program (Medi-Cal).

6.2.3. Ensuring Access to Care and Treatment

Another aspect that must be addressed and researched in the future is ensuring that in parallel with widespread testing, healthcare settings are able to provide treatment or sufficient linkage to treatment resources and referrals for those who test positive. It is estimated that of the 1.2 million people living with HIV/AIDS today, approximately half of them are not receiving care for their disease (Kates and Levi, 2007). If an increasing number of undiagnosed HIV positive individuals are being identified, current available resources might not be able to support this influx of new patients.

Moreover, we must also ensure that treatment is affordable for these patients as it is unethical to diagnose someone with a disease and not also provide an avenue for treatment. A typical antiretroviral drug regimen costs approximately \$14,000-\$15,000 per person per year (Kaiser Family Foundation, 2006). This estimate does not include costs for other types of drugs that PLWH may need for other concomitant health conditions. PLWHA are more likely to be uninsured or covered by public insurance (Medicaid and/or Medicare), be unemployed or have annual incomes that are less than \$10,000 (Schiller, 2001; Kaiser Family Foundation, 2008b). Thus, a large proportion of PLWH do not have the means to pay for their care on their own. States will need to examine the funds earmarked for AIDS Drug Assistance Programs (ADAP), which provide HIV prescription drugs for low-income individuals with limited or no prescription drug coverage.

Moreover, the federal government should consider passing a recently introduced bill, titled Early Treatment for HIV Act (ETHA), which would allow states to expand Medicaid coverage for HIV-positive individuals through an enhanced federal matching rate. Current Medicaid legislation does not provide coverage for HIV-positive individuals unless they are

disabled, which is defined as having AIDS and becoming disabled by this disease.

Previously, when Social Security first classified AIDS as a disability, successful treatment for HIV/AIDS did not exist (Kaiser Family Foundation, 2008b). This portion of the legislation is unfortunate because early treatment initiation can prevent irreversible immune system damage and result in improved healthcare outcomes.

HIV/AIDS continues to be a significant public health problem in the United States. Current testing initiatives are heading in the right direction, but more must be done to ensure that more individuals are tested for this disease at least once in their lifetimes. Since the beginning of the epidemic, HIV has been highly stigmatized making it difficult to fully address the social and environmental factors influencing transmission and treatment seeking behaviors. Nevertheless, all future testing initiatives must find that balance between encouraging and promoting widespread routine testing, ensuring confidentiality of results and sufficient linkage to care is provided, and ensuring sufficient informed consent.

BIBLIOGRAPHY

- Bachman, J. (2003). The Patient-Computer Interview: A Neglected Tool That Can Aid the Clinician. *Mayo Clinic Proceedings*. 78:67-78.
- Brown, J., et al. (2007). Routine HIV Screening in the Emergency Department Using the New US Centers for Disease Control and Prevention Guidelines. *Journal of Acquired Immune Deficiency Syndrome*. 46:395-401.
- Burke, R.C. et al. (2007). Why Don't Physicians Test for HIV? A Review of the US Literature. *AIDS*. 21(12):1617-1624.
- Burrage, J.W., et al. (2008). The Centers for Disease Control and Prevention Revised Recommendations for HIV Testing: Reactions of Women Attending Community Health Clinics. *Journal of the Association of Nurses in AIDS Care*. 19(1):66-74.
- Cathcart, R. (2008, October 2). California to Cover Cost of Screening for HIV. *New York Times*. Retrieved from <http://query.nytimes.com/gst/fullpage.html?res=9D01EEDF1F3AF931A35753C1A96E9C8B63&sec=&spon=&emc=eta1>
- CDC. (1987). Perspectives in Disease Prevention and Health Promotion: Public Health Service Guidelines for Counseling and Antibody Testing to Prevent HIV Infection and AIDS. *MMWR*. 36(31):509-515.
- CDC. (1993). Recommendations for HIV Testing Services for Inpatients and Outpatients in Acute-Care Hospital Settings. *MMWR*. 42(No.RR-2): 1-10.
- CDC. (1995). U.S. Public Health Recommendations for Human Immunodeficiency Virus Counseling and Voluntary Testing for Pregnant Women. *MMWR*. 44(No.RR-7).
- CDC. (2006). Revised Recommendations for HIV Testing of Adults, Adolescents, and Pregnant Women in Health-Care Settings. *MMWR*. 55(No. RR-14): 1-16.

- CDC. (2008). CDC HIV/AIDS Facts: New Estimates of U.S. HIV Prevalence, 2006. Retrieved from <http://www.cdc.gov/hiv/topics/surveillance/resources/factsheets/pdf/prevalence.pdf>
- Corneli, A., et al. (2008). Patient and Provider Perspectives on Implementation Models of HIV Counseling and Testing for Patients with TB. *The International Journal of Tuberculosis and Lung Disease*. 12(3):S79-S84.
- Glaser, B.G. and Strauss, A.L. (1967). *The Discovery of Grounded Theory: Strategies for Qualitative Research*. New York: Aldine de Gruyter
- Haukoos, J.S., Witt, M.D., Coil, C.J., Lewis, R.J. (2005). The Effect of Financial Incentives on Adherence with Outpatient Human Immunodeficiency Virus Testing Referrals from the Emergency Department. *Academic Emergency Medicine*. 12:617-621.
- Haukoos, J.S., Hopkins, E., Byyny, R.L. (2008). Patient Acceptance of Rapid HIV Testing Practices in an Urban Emergency Department: Assessment of the 2006 CDC Recommendations for HIV Screening in Health Care Settings. *Annals of Emergency Medicine*. 51:303-309.
- Janssen, R.S. (2007). HIV Testing: Rationale for Changing Recommendations. *Topics in HIV Medicine*. 15(1): 6-10
- Kaiser Family Foundation. (2006). The Role of Part D for People With HIV/AIDS: Coverage and Cost of Antiretrovirals Under Medicare Drug Plans. Retrieved from <http://www.kff.org/hivaids/upload/7548.pdf>.
- Kaiser Daily HIV/AIDS Report (2007a, February 5). Texas AG Abbott Rules That State Law Permits Prison Officials To Mandate HIV Testing Among State Prisoners. Retrieved from http://www.kaisernetwork.org/Daily_reports/rep_index.cfm?DR_ID=42706
- Kaiser Daily HIV/AIDS Report (2007b, September 26). House Passes Bill That Would Alter HIV Testing Requirements for Prison Inmates. Retrieved from http://www.kaisernetwork.org/daily_reports/rep_index.cfm?hint=1&DR_ID=47754

- Kaiser Daily HIV/AIDS Report (2009, April 8). U.S. Launches Five-Year, \$45M Domestic HIV/AIDS Awareness Campaign. Retrieved from http://www.kaisernetwork.org/daily_reports/rep_index.cfm?hint=1&DR_ID=57912.
- Kaiser Family Foundation. (2008a). HIV Testing for Mothers and Newborns, February 2008. Retrieved from <http://www.statehealthfacts.org/comparetable.jsp?ind=563&cat=11>
- Kaiser Family Foundation. (2008b). HIV/AIDS Policy Fact Sheet: HIV Testing in the United States. Retrieved from <http://www.kff.org/hivaids/upload/6094-083.pdf>
- Kaiser Family Foundation. (2009a). HIV/AIDS Policy Fact Sheet: The HIV/AIDS Epidemic in the United States. Retrieved from http://www.kff.org/hivaids/upload/3029_10.pdf
- Kaiser Family Foundation. (2009b). 2009 Survey of Americans on HIV/AIDS: Summary of Findings on the Domestic Epidemic. Retrieved from <http://www.kff.org/kaiserpolls/upload/7889.pdf>
- Kates, J. & Levi, J. (2007). Insurance Coverage and Access to HIV Testing and Treatment: Considerations for Individuals at Risk for Infection and for Those with Undiagnosed Infection.
- Katz, A. (2001). HIV Screening in Pregnancy: What Women Think. *Journal of Obstetric, Gynecological, and Neonatal Nursing*. 30:184-191.
- Kubler-Ross, E. (1969). *On Death and Dying*. London: Collier-MacMillan.
- Maher, Sean. (2008, December 1). Activists Say Awareness, Testing Key to Tackling HIV/AIDS. *Oakland Tribune*. Retrieved from http://www.insidebayarea.com/oaklandtribune/localnews/ci_11114732?source=rss
- Mahajan, A.P., Stemple, L., Shapiro, M.F., King, J.B., Cunningham, W.E. (2009). Consistency of State Statues with the Centers for Disease control and Prevention HIV Testing Recommendations for Health Care Settings. *Annals of internal Medicine*. 150:263-269.

National Academy for State Health Policy. (2000). ERISA Preemption Primer. Retrieved from http://www.nashp.org/Files/ERISA_Primer.pdf

Schiller, J.S., and Bernadel, L. (2002). Summary Health Statistics for the U.S. Population: National health Interview Survey. *Vital Health Statistics*. 220:1-101.

Simpson, B.J., & Forsyth, B.W.C. (2007). State-Mandated HIV Testing in Connecticut: Personal Perspectives of Women Found to Be Infected During Pregnancy. *Journal of the Association of Nurses in AIDS Care*. 18(5):34-46.

Stegmeir, M. (2009, May 1). Planfield Man Gets 25 Years for Transmitting HIV. *Waterloo-Cedar Falls Courier*. Retrieved from http://www.wcfcourier.com/articles/2009/05/01/news/breaking_news/doc49fb4f4b33dc0897631615.txt

Stemler, S. (2001). An Overview of Content Analysis. Retrieved from <http://pareonline.net/getvn.asp?v=7&n=17>

Zetola, N.M., et al. (2008). Simplifying Consent for HIV Testing is Associated with an Increase in HIV Testing and Case Detection in Highest Risk Groups, San Francisco January 2003-June 2007. *PLoS ONE*. 3(7):e2591.

APPENDIX A: TABLES

Table 1. Updated CDC HIV Testing Recommendations
<p><u>Non-pregnant Adults and Adolescents</u></p> <ul style="list-style-type: none"> • Routine, voluntary screening for all individuals 13-64 years old, not based on risk • Repeat annual testing for persons with known risk • Screening performed on opt-out basis, patients still have opportunity to ask questions and decline testing • Pre-test prevention counseling no longer required • Separate written informed consent no longer required, verbal consent is sufficient • General consent for care considered sufficient as long as patient is told HIV testing may be included • State and local regulations should be reviewed and revised as needed <p><u>Pregnant Women</u></p> <ul style="list-style-type: none"> • Universal opt-out screening <ul style="list-style-type: none"> ○ HIV testing included in panel of prenatal screening tests ○ Consent for prenatal care includes HIV testing ○ Patient provided opportunity to decline testing • Second test during third trimester of pregnancy for women who are at risk or are receiving care in a high-prevalence healthcare facility • Opt-out rapid testing for women of undocumented HIV serostatus in labor or delivery • Testing of newborns if mother's HIV status is unknown

Table 2. Demographics of interviewed participants		
Race	N	%
Black	8	80
White	2	20
Other	0	0
Gender		
Male	8	80
Female	2	20
Insurance Status		
Public	7	70
Private	1	10
Uninsured	2	20
Highest Level of Education Completed		
Less than High School	2	20
High School or GED	4	40
Some College	2	20
College	2	20
Advanced Degree	0	0
Annual Family Income		
Less than \$20,000	7	70
\$20,000—\$50,000	2	20
\$50,000—\$100,000	0	0
Greater than \$100,000	1	10
Employment Status		
Employed	1	10
Unemployed	9	90

APPENDIX B: FIGURES

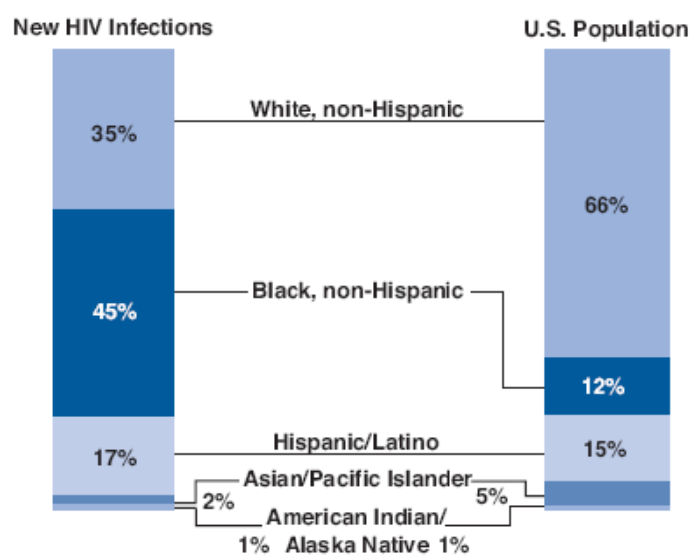


Figure 1. New HIV infections by race/ethnicity and their representation in general population. Adapted from Kaiser Family Foundation, 2009a.



Figure 2. Grounded theory data analysis process used to determine major themes regarding patients' perspectives on different models of HIV testing.

Trend in Share Naming HIV/AIDS as Most Urgent Health Problem

Percent of the public naming HIV/AIDS as the most urgent health problem facing the nation in an open-ended question



Source: Kaiser Family Foundation surveys



Figure 3. Decreasing percentage of Americans who name HIV as most urgent health problem. Adapted from Kaiser Family Foundation (2009).

APPENDIX C: RECRUITMENT FLYER

DREXEL UNIVERSITY SCHOOL OF PUBLIC HEALTH
& COLLEGE OF MEDICINE

Patient Perspective on HIV Testing Research Study

Be a part of an important research study on improving HIV testing rates in the U.S.

Are you:

- **Between the ages of 18-64?**
- **Available to speak for about 45 minutes?**

If you answered yes to these questions, you may be eligible to participate in this study. You do not need to be HIV/AIDS positive to participate.

The purpose of this study is to survey patients' opinions on HIV testing and what can be done to increase the rates of HIV testing in the U.S. No HIV testing or treatments will be given out.

If you are interested, please contact **Sirena Sun at 240-274-7527** for additional information.



APPROVED
OFFICE OF REGULATORY RESEARCH COMPLIANCE
Protocol No. 18007-01P
App. Date 02-04-2009
Exp. Date 02-03-2010

APPENDIX D: SEMI-STRUCTURED INTERVIEW QUESTIONS

Patients will first be provided an overview of the purpose of study.

Introductory statement: “Thank you for your willingness to participate in this research study today. Before we begin, I will first explain to you a little bit about the purpose of this study and what we’ll be discussing today. Please feel free to stop me at any time if you have any questions, would like me to clarify anything, or would like to withdraw from the study. Please know that withdrawing from the study will not in any way affect the care that you currently receive from the clinic.

“The purpose of today’s study is to determine which features of certain types of HIV testing are most appealing to patients. We hope to use this information to generate recommendations for future HIV testing initiatives so that ultimately we can decrease the rate of new HIV infections in the U.S.

“Today I will be asking you questions about your HIV testing history (if the participant is HIV positive), go over with you current types of HIV testing models, and ask you for your opinion about these testing models. Are there any questions you would like to ask before we begin?”

HIV Testing History

Could you tell me a little about the circumstances surrounding when you were first tested?

Where did you obtain your test?

How long ago was the test?

Anonymous or confidential test?

What motivated you to get tested?

When you received your test result, how did you feel?

Do you obtain tests regularly?

If yes, why?

Did you experience any difficulty in getting tested?

If yes, can you list and explain them?

Did you receive any type of pre and/or post-test counseling?

If yes, did you feel that it was or was not helpful/beneficial?

Changes in CDC Recommendations

Recently in 2006, the Center for Disease Control (CDC) changed its recommendations for HIV testing. Under the old CDC recommendations, HIV testing was conducted on a voluntary, opt-in basis with counseling and testing linked together (also called voluntary counseling and testing or VCT). Under VCT, a patient would have to specifically request for an HIV test, provide written consent, and undergo pretest counseling. However, the CDC felt that these requirements were themselves a significant barrier to widespread testing, and to obtaining an HIV test in general. So, with the new recommendations, all patients are tested on an opt-out basis where you are told that an HIV test will be performed and consent is understood unless you specifically decline the test. Separate written consent is no longer required. Moreover, patients are no longer required to

get pre-test counseling where their physician would discuss with them ways to reduce risky behaviors that would increase their risk in contracting HIV.

- Were you aware of these changes?
- Why do you feel these changes were made, and what is the purpose of these changes?
- What is your opinion on these changes?
 - probe as needed: ask about removal of pretest requirement, informed consent.
- Do you feel these changes will motivate more people to get tested? Please explain your answer

Alternatives to Opt-Out

Incentivized Testing

Other than opt-out, some groups have tried incentivized testing to increase testing rates. One example of incentivized testing is providing someone with a gift card to a grocery store for completing an HIV test.

- Do you feel that incentives will increase number of people who get tested? Why?
- List types of incentives- gift card to grocery store, concert tickets, money. Which one do you feel will motivate people to get tested? Why?
- Would you list a few that you believe would be successful?

Mandatory testing

Another alternative testing method is mandatory testing. Under mandatory testing, people are required to obtain an HIV test. One current example is Connecticut, which requires all pregnant women to get tested. Another example is one where individuals would not be able to file their income tax form unless they have proof that they had taken an HIV test. The individual could go to an HIV clinic, take a test, and receive a 10 digit number that they would write down on their income tax form. The IRS would not know the result of the HIV test, just the fact that you had taken one.

- What is your opinion on mandatory testing? Anonymous mandatory testing?
- Do you think it is fair?
- Do you feel that mandatory testing will be successful in increasing number of people who get tested?
- Other than the examples of mandatory testing that I have listed, are there any that you feel would be successful?

Ending the Interview

Before we wrap up this interview, would you be willing to provide me some general information about yourself, such as your age and so forth?

Obtain Patient Demographics

Age: (no birth date, only age in years or birth year)

Gender

Race/Ethnicity

Insurance status: private, public (Medicaid), uninsured

Family income: below \$20,000; \$20,000- \$50,000; \$50,000-\$100,000; above \$100,000

Highest level of education completed: less than 8th grade; some high school; high school or GED; some college; college; graduate school

Employment status: employed, unemployed

Thank you again for your time and willingness to speak with me today. Do you have any questions or comments about anything that we have discussed in this interview?

Appendix E- Interview Transcriptions

Subject #001

Interviewer: I just wanted to first thank you for being willing to speak with me today. Before we begin, I will go ahead and reiterate what this study is about, and again if there is anything that you are not clear about or if I'm speaking too fast feel free to stop me at anytime. So again the purpose of this study is to determine the features of different types of testing that is most appealing to patients and just to get your opinion on that. We hope that this information can help us improve testing initiatives ways that we can do to get people to get tested. I'll ask you about your testing history and get your opinions on these different types of testing. And you again can stop me at any time. If there are any questions that you don't feel comfortable responding to you can definitely ask me to skip over it, it won't affect your treatment or anything. Do you have any questions before we start?

Subject 001: No.

Can you tell me a little bit about the circumstances surrounding when you were first tested?

Uh, I think it was when it was the HIV/AIDS first hit the Inquirer on a Sunday I'll never forget it. It said something, headline about AIDS, and my dad gave me the paper and told me to watch myself. A few months later I went and got myself tested and I came up November '91 I was positive. I went to the health center 1 off of Broad and Lombard, and I came up positive.

You decided yourself to get tested?

Right. I mean I was living... um. I'm homosexual, and everyone thought it was a gay disease at the time. And my sexual activity was high.

And you said you tested back in the 90's?

Yes, '91.

Was this an anonymous or confidential test?

Anonymous

And you said it was the newspaper that motivated you to get tested

Yes that's right

And when you received that test result, how did you feel?

Hurt broken depressed, like it was the end of my life

How long did it take you to come to grips with the diagnosis

About five years

Did you see a doctor shortly after?

No

When did you wind up seeing a doctor for the first time?

I went into a program, a drug and alcohol program. That's when I found... cause everyone around me were dying, all my friends. And when I went into a drug and alcohol program that's when I met people that was living with the virus, and they told me that they were going to support groups and they told me about you can live with the virus. Because you know, I was taking a few different cocktails. The first one was AZT. And that started during my... that's why I stopped. This was before I went into the program. It was turning my skin grey. That's how strong the I guess the toxins were in there. So I stopped taking that, and that's when I got a doctor and they put me on dexovan [spelling?]. I think it was the health center that put me on AZT. That's when I found out about... what do you call it? I can't think straight since I'm on there (laughs) What do they call the doctors like doctor Sarah?

Infectious disease specialists?

Yeah, yeah infectious disease. And I've started feeling better, but I've never been sick though, never gotten sick.

Do you obtain tests regularly?

You mean for my CD4 and all that?

I guess was that the very first time you got tested or have you tested before that?

Before the 91 you mean? No, that was the first time. Because basically that's when it became public, the late 80s

Would you be surprised if I told you that HIV/AIDS was recognized in 1981?

Yeah, because I think they supposed that it came from Africa or somewhere over there. And people weren't getting it in the US. It wasn't that... you know. But when it's like that epidemic, I thought the government put something in something or, they were just singling out gay bars or clubs and stuff.

They actually thought it could be poppers in the beginning, they had no idea it was a virus.

Did you experience any difficulty in getting tested?

No, I mean it was like you wanted to have a coat over your head because you didn't want nobody to know. It was kind of shameful, you know. And you didn't know if it was um airborne, they didn't know a whole lot about it so it was real scary.

So because of that kind of mystery surrounding it, it was really difficult to...

Yeah right, you didn't... Yeah, right you didn't want nobody to know.

When you got tested, did you receive any pre or post testing counseling? Where they told you what the risks were, and how you could change your behavior to avoid infecting others, that type of counseling?

It was there, but it wasn't as deep as it is today. We came a long way. Where as though you can go anywhere and everybody knows about it. So, I'm grateful for that. Cause I never knew that...I don't think that... maybe it was 10 years ago... and I found out that you can get reinfected, you know what I mean. It's not like one. You can get reinfected with a different strain of HIV. Or you know, you could have sex with someone and get infected with the AIDS virus because of the different strains.

So you feel that it was beneficial to get this type of counseling?

Oh yeah definitely.

So now I'm going to tell you a little bit about the changes in trend going from the voluntary counseling that required all the paperwork to the opt-out. So um in 2006 the CDC changed its recommendations for all the different health centers like Health Center 10 and hospitals and things like that and the CDC basically told everyone that it would be better to do the opt-out testing where the doctor tells you that I'm going to do some blood work and I'm also going to test you for HIV and unless you say no I'm going to go ahead and test. The idea is that if you treat HIV like any other disease like high blood pressure or cholesterol, it'll remove the stigma surrounding it, and make it more acceptable and get more people to test. Some people feel that by making it opt-out, people won't get the counseling with it. By taking away the written consent, people aren't really informed what it means to get tested. Were you aware of these changes?

No I wasn't. If I stuck around for more group meetings, I would have been you know.

I didn't even know myself either so you know.

I mean it's a good thing. For a person, any human being on this earth, I don't know why they wouldn't want to be tested. You're losing.. you're sick. It's like you being in an accident, they don't know what to do. You could infect someone you got a cut they got a cut. Any number of things, so it's very important and I think people should know these things.

So people should know just in case.

Right, right. You could be allergic to medication, and you know.

So it's something you should just know about yourself, like you said it was a cancer, just to take care of yourself. Now why do you feel these changes were made?

People are still in the closet about this disease. It's a very scary thing, but it's something that everybody deals with. The only people I know who don't have sex are the monks or you know what I mean. Today's society, it's such a shame that so many young children, and when I say children I mean ages 12-18, they're having unprotected sex and they're the one that are getting infected, and that's not giving them a strong life to live b/c you want to be able to have children, and I don't want to have no children because (I mean I wouldn't have them anyway, but even if I wanted to, I wouldn't want to have none because I wouldn't want to affect that baby with the 50-50 chance, I

want to say there's a 30-70% chance for that baby to be infected. And it's not right to bring someone into this world not knowing if they're going to be positive or not. I wouldn't take that chance. I'm not saying it's a death sentence, but it's more stress to add on someone's life.

And then that means I'm going to need help, from the city. It's not right to bring someone into life, or for that female that's going to have my baby to be infected. It's not right.

So how do you feel about removing that counseling requirement? I know you said your counseling was beneficial...

I think people should be because, not that I'm trying to find another way to spend tax payer money, but I think it's important. people should have counseling before, during and after, because your whole life can change. It's going to be a lot, it's going to be stress, people are going to worry. A lot of people can't handle this thing. For me, I had a feeling that I had it so it didn't bother me that much, plus I was drug addicted, so I just medicated myself through the whole thing. And you know, God's not going to put nothing on us that we can't handle. Even though a lot of people don't look for him, he can't remove things. But I think counseling is important just to help people. Or send them somewhere. Don't drop a bomb on someone and leave them. That's the worst thing.

So do you feel that your drug and alcohol program gave you an extra support system?

Oh yeah, because people in drug and alcohol accepted me much faster with my HIV than your friends some of my friends would. Before I even told people, bring it up in conversation, people would say negative things and they have no idea about what HIV or AIDS is they didn't even know what the abbreviation is.

So if we had taken away the counseling, and referring to support groups sufficient?

Yeah, I mean they would probably be uncomfortable because it's kind of hard it's different when you in a support group for drug alcohol, you have a vast number of them. I'm being by myself, I'm a loner and I'm going to this meeting, I hope nobody sees me going into this building. One on one counseling is very important for someone who is newly diagnosed, or someone that's going to be tested regardless of what the result is. Because in everybody's family, I'm going to say 70% of US, someone's cousin, someone is going to be positive. And it's a shame that it happens that way, and I wish it wasn't, but it does.

So definitely still counseling?

And even people that aren't, everybody should know about it. Even people who aren't positive should know about it. Like in churches, they didn't want you in church. They don't even like talking about sexuality in churches, but we've come a long way. But if more people know about it, it can help

So what is a barrier to getting tested for some people?

Some people is uneducated. They should bring this into schools. It should be, I forgot what class you would take... biology?

I think it's sex ed?

Yeah sex ed. On a weekly basis they should be talking to people about this. They should have it in churches. They should have more programs on tv about it. I mean they got this CSIs and these game shows talk shows, they have no educational shows about this and this is affecting everybody. Can you imagine if they did do that. I mean how much... the ratings might be low... I don't know. They might be high. I hope people would watch it.

What type of program? I know on tv they have those five minute blurbs.

They should at least start out with half hour show. And it shouldn't even be on channel 12. It should be on bigger channel, people need to know. I bet if they did this 10-15 years ago, I bet a lot of people wouldn't be positive. I know it only takes a few seconds to get a condom, but that comes with people breaking or people want to have fast sex. That's how I acquired it through sex. But it was a hush-hush thing back then.

So just to make sure that I understand you, you feel that educating people is the best way to get more people to get tested?

Yeah, and just letting them know that it's okay.

So letting them know that it's not a bad disease, it's just like getting cancer.

Yeah, like I said back then when they thought it was a gay disease, they were bleaching everything, they didn't want to hug you let alone give you a kiss or something. It was terrible. They didn't even want to sit next to you and eat because they think that if you sneeze they can catch it. Just the small things about it.

What do you mean by small things?

You know, silverware, coughing, touching. As long as you don't have cuts on your hands. But even if you both have cuts and you touch blood to blood, it doesn't mean you going to catch it.

So removing these types of false myths

Yeah, like you know with the barbershop thing. You can't get it unless you get cut, but there's a very small chance that you can get it. But just educating people.

But other than opt-out, we've started doing incentivized.

Which I think is not good, if it's going to help, yeah, but I don't think you should have to. It's good that you're doing it. Is the number going up with people getting tested? I guess it is, probably yes? That's a question.

It's still a relatively recent thing, we don't have a lot of data yet, but it's an idea that people are tinkering around with. So I know you mentioned that people shouldn't have to because people should already want to. Could you go back and repeat what you had mentioned before?

It shouldn't be necessary for people to be paid to find out if they have HIV or AIDS because it's your life. It's like you going to the doctors like I said to find out you know. You don't want to be having unprotected sex with all these people and then come to find out that you're positive. Or you don't want to be having unprotected sex with people and you're negative but you don't know what they have. By all means you should be tested even though you should be using protection when you have it but still, you know what I mean. You could be bringing another life into this world and you don't know. And it's not just about the HIV or AIDS, it's about any STD that could be out there because they're out there and you can't tell just by looking. So, it's important. So I really don't think people should actually have to pay someone to find out, to test somebody to find out if they're positive. But by all means, since the numbers are so low I guess you know, it's crazy that they're doing that.

So people should be more aggressive in their own care.

Exactly, exactly.

If we did have to do incentives, what kind would be most motivating? Movie tickets, gift certificates to the mall, things like that?

I think go the most inexpensive way. Cause they got this thing, Action Aids has... they'll give us movie tickets if we call, theater tickets you know, we can see plays and whatever. And this is strictly only for people with HIV or AIDS. So I guess the most inexpensive way. And a lot of kids like movies. So for the younger generation I would say movie tickets even though they love the mall too, but it'd seem like it'd be more inexpensive to give movie tickets than gift certificates to go to the mall.

Mandatory testing, example of pregnant women in Connecticut, linking testing with filing tax returns.

That's a good idea, the tax returns because it's not asking you to tell them if you're positive or negative just the fact that they know that people are having sex, and people need to know if they're HIV positive or negative because it's an epidemic, it's costing... first of all it's costing so much money and it would be much cheaper if people knew so they would take precautions so you won't affect anybody else so I think it's very important whatever all means that they have to do to do this. It's not about the government getting in your business, it's about the government trying to help stop the spread of HIV/AIDS, that's all... that's the bottom line, they're trying to help stop it, that's it. And it's never ending. And we've come a long way like they said. You know with all the medications, case management, information, it's out there. And people are like you know... even if you're married, been married for 50 years, still you know... it's... just do it. It's nothing to be ashamed of, it's just a health, just to find out. It's our life, it's my life, so I think it's important.

So some people feel that mandatory interferes with someone's right to chose. How do you feel about that?

I don't think it does. It's the bottom line, if they look at the big picture... I think the best way to go about that is to give them statistics on it. What age group, what race is high... is high risk. Regardless, like I said if you're sexually active or not, it's important to know...um... if you're positive. If you're negative, okay it's a one shot deal. Even if they keep do asking you every six years, you should be tested. Just like you should be tested for cancer... every.. women should be tested for cancer, men should have colonary uh, it's just a part of life. You have a disease out there don't you

want to know regardless of what your sexual orientation is or if you been married, anything.... You never know. Things pop up. There are weird accidents that happen out there. The first thing you going to be like if you're positive like woah how did I get this? It don't matter how you got it, you got it and best take care of it. So I think it's important.

So definitely trying to get people to see HIV like any other disease.

Yeah, it's just a... I keep calling it... going back to it's a cancer that you can't get rid of right now. I went from HIV to AIDS to undetectable to HIV. Now explain that. I mean it's unexplainable but I have records. My CD4 count... since they say that once you go below 200 you're HIV, I mean AIDS. Then I was on fortibase [spelling?] that made it undetectable. And now my CD4 is 160 my viral load is 488. I mean sorry, my CD4 is 488 and my viral load is 160. There as a time when I was undetectable. And I've never been sick. It's nothing to be ashamed of, it's just something that happened. I'm just one of the "chosen ones," I'll call myself. And some of us will be chosen to get this disease.

So definitely have to take care of yourself

Right, exactly. Probably just make you a better person.

Mandatory improve number?

Yes definitely.

Other than the examples I gave you, are there any other ways that you feel could be done to get people to test?

Well it should be mandatory number one. When they go to school. And start them off young too, maybe even start them off even younger. Like you know, when you go to kindergarten they should start them off then. But it's just a matter of... I'm trying to think of how to keep people being tested, like maybe in schools after they go from preschool to elementary, they should keep testing young people. Adults that's a hard bone to chew, because it's so hard... once you become an adult it's hard to make adults do things. So, that's the biggest question, that's the million dollar question. How you get adults, anybody between the ages of 18 to you know. Anyone that's not married ... to be tested. Because you know they're going to have sex or want to have sex. How to make them... you shouldn't have to give them movie tickets or nothing like that. They should want to do this thing. That's the biggest brainstorm.

How to get people to want to get tested.

Right, from 16, that age on.

So how can we get people to want to be tested?

That's the big question, like y'all said you're giving out movie tickets or gift certificates to the mall. You know I can't keep stressing how important it is. That's a hard question. That's a real hard question. That I'll have to think on a little bit.

While you're thinking about that, I'll just collect a little information about you in general.

Age 47, male, black, Americhoice (welfare/SSI), below \$20,000, GED, unemployed

I guess we can go back to the original question.

That's a hard question. That'll take a few days to think. I'm just trying to think. Like you said, movie tickets and... I don't know. Like you said, I think that's good because people are working and as far as the government should make them... file taxes.. in order to get your check you need to be tested. Job applications. But when they do it of course it's anonymous. You could be applying a job as a waiter or a cook and they find out you're positive, first thing you know... some kind of uh... or when they vote... people love to vote... even though a lot of people still don't, but you know. I know if you're in rehab, of course prison. Do they make you in prison?

I think they're starting to.

They should be mandatory when you go to prison, and if you're going to rehab. If you're on any kind of government assistance. It's easier like that, you know what I mean. I mean because in a way if you want that check you got to be tested. So it's easier that way I would say. The hard part about it is anybody that's just... regular joe blow, you know, that doesn't need no assistance from the government it's harder to make that person because... they're self...yeah... that's anybody that has an education that's going out on their own doing things the way life's meant to be for you know...go to high school get a job. It's harder for that person you know... even though they have a social security number but it's harder to make somebody say oh stop you need to go get your HIV test. But you would think they're smart enough to go out and do that versus somebody who's drug addicted or you know. Because us drug addicted people we're living life the way we want to, we're having sex the way we want to we're not even going to the doctors. So that's why it's important for people in rehab to go out and get tested because we're out there having habitual sex. So my thing is how to make the adults, young teen adults get tested. But you think that person would be smart enough to know to go out and be tested. But I think there's probably a big number there, a wide number of people there that's not getting tested that think I'm not going to be infected, or I'm not infected, not knowing that 2 years ago that unprotected person you had sex with was positive and now you're walking around with a virus in you and you're not being tested, and you're going to the doctors because you had a cough but knowing you could be walking around with pneumonia because of a complication from the virus. It's hard to figure out how to make those people be tested. It looks like you all got the younger generation cornered because you could give them movie tickets or mall vouchers but what about the other part that they don't need no vouchers and they can buy their own tickets they got enough money to go ahead and do that. That's the ones that probably where when if you want to file your taxes. That's the percentage that needs to be tested for the virus. It's a no win situation because you always got, it takes what.. just a few people not to get tested and there you are and they have unprotected sex.

Any other questions/comments?

none

Subject #002*Circumstances when first tested*

When I was first tested, I kinda went through it, you know?

What made you get tested the first time around

I just...as a matter of fact I found out... I went to the blood bank to give blood. And when I went back, it's like they kept saying no, we can't use you because you have to go see a doctor and bring back this note, and I was like what's going on, I didn't know. And I goes over the way to Hahnemann, and they told me I was HIV positive and stuff like that. I was going through it for a minute. I started seeing a mental health and all that. Just happened, losing my mind. I just recently got a grip. And this was in '98.

So this wasn't a specific test for HIV ,it was done through the blood bank.

Yeah, that's right. That's how I found out.

After doctor told you were HIV positive, how did you feel?

Like it was the end of something, you know. I mean... I still feel nobody should give nobody this, you know? Because of this, people don't bother me or none of that. I wouldn't give this to nobody. I can't see nobody giving nobody this. And I know a girl that's out there and she's giving this to everybody.

Did you see doctor after got result?

Yeah, first I went to U of Penn, then I went to Mary Howard, then here with Hahnemann.

So you've been with the Partnership for many years then?

Yeah

So you didn't receive any type of counseling after you received the result?

No.

Did the doctor tell you what the result means and...

Yeah, and then they said they had these groups but I never went. I can't see myself being surrounded by a bunch of people talking about it. Yeah, it just ain't me.

It'd be uncomfortable?

Yeah, yeah. I mean nobody in my family know I got it, except for my mom and she died. But she don't tell nobody either.

Do you feel if the doctor had talked to you more about it, do you think it would have helped you?

Yeah, I think it would have helped me a bit. I'm sure it would have.

So they told you the result and gave you groups, and that was it?

Yeah, pretty much.

Changes in testing recommendations, going from VCT to opt-out. Belief that opt-out will increase number of people who get tested, reduce the myths surrounding the disease...

You got some people who have the disease and don't do nothing about it. Why is that?
I guess it just depends on the person. But they hope that by making these changes, more people will get tested, make it seem like any other disease.

So a lot of people have it?

Yeah, a lot of people do, and they don't know

So tell me, if you never get tested, you would never find out? I mean, don't nothing let you know that you have it or whatever?

If they don't like give blood or things like that, I don't think they would ever find out...know soon enough. The idea is if you test regularly, you can know earlier
 Oh right so to prevent...yeah.

Right, so you can start your drugs earlier, live longer. a lot of people don't find out until really late, and it progresses to AIDS, their CD4 count gets really low.
 So under 500, you're history then?

Um, I think ideally you should start your treatment before your count gets to 350. But sometimes people don't find out until really late into the disease.
 Oh okay.

CDC taking away pre-test counseling.

Some people don't want to hear that they actually have it. Took me for a loop when I found out

Yeah it can be very difficult. What is your opinion on these changes? Will it help?

I think it would probably. I think it would.

Taking away pretest counseling help?

They're going to take it away?

They're saying you don't have to do the counseling about what the test means, what it means to test positive before the test. Good/bad? Keep it?

I think they should keep it.

Why is that?

I feel everyone should know what is wrong with them, you know. Why not let a person you know? And everyone should get tested, you know what I mean? Especially if you don't have it because you don't know who they been with. I look at it like that. I think everyone should get tested. Specially if they ain't safe sex. So I think everyone should get tested.

Incentivized testing, movie ticket to go get tested as example, gift certificate to grocery store. Will it help?

Yes, yes, I think they would

Other incentives that will get people to test.

If they being compensated, yeah.

Any kind compensation? Regardless if it's money or movie tickets?

Yeah, yeah, they would.

Mandatory testing, you have to get tested, you can't say no. Example of pregnant women in Connecticut.

Yeah okay, but what if she didn't want to do the test?

Then they would just be too bad, they would go ahead and test her.

That's like interfering with someone's rights. How can you do that to someone who don't want it. That's not right.

Example of federal prisons

Yeah they're testing you in prison. I was there in 2007. They test you anyways, don't matter if you want it or not, you have no choice. Yeah they test you there now. When they test me, I told them you don't got to test me. I know I got it. They were like you serious. I'm like yeah I'm serious I already got it [laughs].

Do you think it's beneficial to do this?

Yeah, I'm sure

But you think it's also not so good because it interferes with rights like you said?

Yeah I think if it's something you don't want, I don't think nobody should be able to you know. You didn't give them the okay. I don't think that's right for them to go ahead and do it. I don't think that's right. Yeah, I don't think that's right. If a person he willing, then I say it's okay. But if a person don't, you know... that's not...I don't think that's right.

How do you get someone who doesn't really do a lot of blood testing, like donate blood, doesn't go to doctor, how you get them to be tested?

Well how you get them to get tested, like you said, if you compensate them, or something coming to them, they will do it. I know a lot of these people out there will.

Give \$5 best way or is there another way you think that will be better?

Yeah, if you compensate them they will, I know that for a fact.

So you're saying that it's not fair to make people do things if they haven't given you the okay?

No, no I don't think that's right.

Other than these three types, are there any other ways? Other than compensating them or making them do it...

Well, I guess talking to them or you know whatever. I mean that gets people to do a lot of things. You got to explain to them what's going on. Not that trickery thing, making them do what they don't want to do that's not

So just going out and talking to people, outreach?

Yeah, yeah.

Where to go? How approach people?

Libraries, you got a lot of these homeless people living around here, down at suburban station.

Demographics

46, male, black, Americhoice (public), below \$20,000, high school, unemployed.

No additional question comments.

Subject #003

Circumstances when first tested, where were you, why did you get tested?

Um, I got tested because when I was incarcerated, my child's mother, well I didn't know. She was pregnant at the time, and we got into a heated debate over the phone and she flat out told me that she was positive and I had it. And that's what made me get tested. Um, again, the first time I got tested was in 1995, and uh, May of 1995, I got my results back and it was negative. And I met this woman, and the next thing I knew, I carried my results with me and I introduced myself to her, but before anything got involved, I asked her about her status as well as she asked me mine, and I showed her my results. But I didn't think about really checking and seeing about hers. And um, took for granted, took it for granted. And next think I knew she was positive and never told me.

So second time got tested...

Yeah, I was positive and it was her. It was in 1996.

How feel when got test result?

I felt...I felt like that was the end of my life. And to be honest with you, I still do feel that way. You know, it's hard for people to accept people who's HIV positive, especially if you're looking for companionship. Um, they tend...they tend to shy away from you. They don't...they don't want to get educated on it. And especially if a person is really healthy anyways. No matter what, they just...they just, I don't know. It's just like they just don't...they think that you got the...they think it's a death sentence. Um, you know I really kinda feel kind of blessed from 1996 to now that I'm not where I've seen a lot of other people are. You know I've seen people who've come to me who are positive, and they like well I wish I could switch places with you, because their health is bad. And I wonder why that this happened to me, and I think that it's nothing but through the grace of god. I still get depressed and angry about it because I don't feel like I'm normal. I don't feel...I feel as though, I don't know, that there's not a person out there for me now.

So it's harder to connect with people because they're scared or they don't understand the disease.

Exactly. Uh, and I know...and it really kind of feels, makes me feel bad. I really get angry. I really really get angry when I see people that...that...just...so naive about the situation and...they will uh, say I'm the hot shit, excuse my language. Or whatever you want to call it. And you know, instead of really getting educated on it, I think science came a long way for us from it. And I hope that they one day do find a cure for it. Um, I just hope that I'll see it within my lifetime, you know. Because I've seen people who died from it when there wasn't...when science wasn't that advanced to where it's at now.

When got test result, see doctor immediately afterwards?

When I got my results, I was incarcerated.

Did they provide you care?

Well, actually, I didn't have. I didn't have that...I couldn't really deal with it at the time because when you're incarcerated, you can't really do...you gotta keep your guard up. Um, and I couldn't, I didn't have anybody really to talk to. I mean I talked to the chaplain. Or uh something like that the chaplain. I mean...I had one person in there that I could just vent out with. But it just wasn't enough. You know um...I tried talking to my father, I called my father when I found out and he wasn't very supportive of me with it. When I told my mother, she thought that I was going to die. Now they both deceased, but...I don't know. I don't know how I would tell my children. You know, their mothers

know, but my children don't know. And I want to be the one to tell them. You know, when they old enough and they'd really understand. As far as their mother-wise, they just don't understand. The one who gave it to me she's deceased now. Complications along with it. And I really believe that god doesn't like ugly. Because just if you's just that naive to give it to me knowing that I'd showed you and how I that upfront with you. And that's why I say I could never do what she did to me. You know, I just can't. I just can't pass it on like that. You know, I was open with their mothers, and explained the situation with them. Look I'm positive, where do we go from here. She was willing to accept me for me. As far as on that part of it. But then as years gone by, we talked and she really really was naive to it. I guess she looked at it really as a lust thing, or she just didn't know what she was getting into. And now she realizes what she's getting into and she chose to back out.

Prevention counseling?

No, actually I took the test, and when I got the results they called me up there, and they sat me down and they just said I'm not going to beat around the bush, I have to tell you you're positive. Right then and there, I just haven't been right sense. I'm dealing with it. I'm trying to learn my role about it, learning more and more each year. And well, sometimes I, I really get depressed about me having it. Because it seems like, like I said, my life is stopped. I got to be, I have to ...any person that I meet, I don't know if it's, if...I don't just come straight out and say look I'm this and this, not less I know it's going somewhere further. If it's going to that next level. And then again, I'm just...I don't know if I should say it in the beginning or wait until it gets to the next level and then the person gets their feelings involved. And then I say well look here this is what's going... because it's going to the next level. And I don't know how they're going to react, well you should have told me this in the beginning or why wait until now when I get my heart involved and you say something. So it's a damned if I do damned if I don't situation. I don't know if you should kiss and tell, or wait...or wait and then kiss. Or wait.

It adds on another difficulty to relationships that are complicated enough to begin with.

So uh, I don't know. That's why I really don't know. I don't know. I really don't know how to deal with that part yet.

So just to go back to the different testing methods. CDC changes. Explanation of opt-out, you have to specifically say no, you don't want to get tested.

In a way I believe it's against their rights.

They still have the option to say no, but they have to specifically indicate no.

Oh specifically indicate, that while I'm testing you for so and so I'm going to test you for HIV. Okay I can see that. But just to go ahead and do it without letting them know, I think that's a violation. Um, like I said I do believe that that's the individual choice. Maybe it's the wrong choice. But that's their choice. You know? I really believe that, that should be up to the individual if they want to get tested or not. Now do I agree with it? No. because uh it can be passed on still. But, what can we do you know? Like I said it's a volatile situation. I don't agree with it, but I think they should come up with another way. But that's not...I don't think that...I still believe that it's the individual's choice. Like I said, if anybody go and uh, go and uh...into a facility and they say well I want to test you for such and such and do you mind if I test you for HIV? Then I can, I can go with that. Because it's that individual's choice.

So do you think doing it this way doesn't give people enough choice?

Uh doing it if they're asking them? Yes I do believe that gives them choice. I do believe that. Yes I do. But the thing is too, what's going to happen if they uh, say yes and they say yeah okay I'll take it and they're not aware of the situation of what can happen, you know? Uh, thinking that oh well, that'll never happen to me, no, and it turns out that they say they'll take the test and it comes back and it's positive. Then what you got then now, you have a whole mind...a different mindset of this person now. They're really going to go through with it. And you have to have the proper staff or somebody that support system to really, really help them. Then you just sent them out on a mission. Because you have some people that really...really uh handle situations in a destructive manner, you know. As far as substance abuse and everything else like that. Um, it's kind of...kind of really touchy. Just really, really touchy. And just to think of and be aware of what you're going to get into, when you're uh... what you're messing with. Innocent people who want to take them surveys.

So you're saying that people need to know what it means to take the test, what can happen to them before they even take the test?

Yeah, I think they should be aware of...of...the downsides of if you are positive and what's going to happen... like hypothetically what if you became positive. How would you feel?

So people need to know...

And uh, I don't know a lot of people probably say well I don't know because I'm not. But it just could happen that you could be you know? And how would you react? Some people like I said, a lot of people just think that that would never happen to me, you know. I ain't getting it, I'm cool. You know, and a lotta people don't understand far as about woman can give it to you in more ways than one. And, and a lot of these men out here go out there doing...I don't know...I'm trying to be nice about it...but uh, [laughs] doing these things to a woman thinking that they can't get it, you know thinking it's only through sex but they're not looking at the vaginal secretions, they're not looking at the breast milk. They're only looking at it through having heterosexual sex. And, and it's just saddening that they're so misinformed. You know? And uh, I say that because I went through it already. You know, I did everything to this day a woman that I thought that you could do when you in love, and it turns out all the things that I was doing was ways that I got contracted with it, you know. And to this very day I look back and I could just really kick myself in the head, you know? Why was I...how could I be so stupid, you know?

So how can we get people to not think that? Why are they not getting tested?

They're scared. They're scared of the virus, and a lot of people think that they don't...it doesn't... it won't happen to them. But more so I think as far as those...me personally I think that's what it is. They're scared and they don't think it can happen to them.

So how can we get people to change their mind if that's what's keeping them from testing?

I think that more so that research gotta come up with something that seems closer to a cure. You gotta be closer to a cure for people to want to get tested. And, and have people realize that it's not a death sentence. You can live with it. If you live right. Um, if you live right and uh, that uh...yeah.

So educate people?

Yes, educating them. Educating them and plus, science has to come up with something closer to a cure.

So if people think there's a cure, people more willing to test?

I think so. Instead of just getting...having a test...being forced to take a test. Um, when you think, when you say oh my god I think I really...or you know. Because one time, I really took a test because I was sick. But it turned out I just had a little flu or something. But, I had uh...I knew what I was doing out there having unprotected sex and things like that and I had gotten sick. So um, that's one of the reasons why I took that first test and it was negative. And I think that's... that forced me to take a test. That's what I mean by being forced to take a test.

Because you were sick...

Yeah because I was sick. And uh I knew that in my mind I was being destructive, and doing...doing destructive behaviors, sexual behaviors, not protecting myself. And that's what made me want to get tested the first time. And it's all on the individual.

Was it hard to get tested the first time?

It wasn't hard. But I was worried also.

So it was that worried that motivated you.

Yeah it was that worried...that worried motivated me to get tested. Um, then when it came back negative I was kind of happy. But then, the second time when I went to get tested...I was...it was...it was another motivation because I wanted to know was this person telling me the truth, that this person had infected me.

Those tests anonymous or confidential?

They were confidential

So they were no name, just number?

Yeah.

Incentivized testing to get people to test. Giving free movie tickets as example. Will this motivate people?

Umm...I don't know. Can we talk about that later? I need to think on it a little more.

Anonymous mandatory testing. Example of pregnant women in Connecticut. Do you think mandatory is a good way to get people to test?

Well, I still say that's against their rights. Me personally I think that's against their rights. It's their choice if they want to get tested or not. You know, do I agree with it? No. [laughs] No, but it's their choice. And we all, we all um we all have to uh make, uh you know that there is consequences of our decisions. Some are good some are bad. But we can't...and...and...I still say that you just can't just force anyone to just...to do something what they don't want to do. And now even though it may be the right thing, you know, but it's up that individual like I said if they want to protect themselves and protect their baby. Yes, they would say well I want to get tested, and I want my baby to know...I want to know my baby's...something you know. Any mother should want to do that on their own. But to make them...no. And that's why I made that...science will have to, or some type of administration will have to come up with something different. Something, something...just something different as far as that that person can feel better about themselves. But now, that they can do it, instead of forcing someone to do something. Because you can't. [laughs].

Lots of people HIV+ and don't know it.

Of course, of course. And I agree with that.

One out of five positive don't know it. Half of new infections caused by those unaware.

And a lot of...a lot of I believe that a lot of them also is...the ones that spreading it around is the ones doing destructive behaviors as far as substance abuse. Um, or females out there that are what you call ladies of the night I guess. And you have the homosexuals too, you know. But they're out there doing destructive behaviors and..and..then these...as far as substance abuse or um, things like that. So, and they have...be having multiple partners. So yes, yes I believe that as part of the ones that's...yeah.

So how do we get these people, the ones doing the destructive behaviors, how do we get them to test?

Oh goodness, that's a good question. Uh, I don't know. As far as I'm trying to think...I'm really, I don't know because being so me personally by me being on both sides of the tracks with the destructive behaviors and all that. So, I can't...I really don't have an answer for that yet.

Making them get test it, making it by law to test it mandatory?

No, because if they're going to do it, that would probably force them to do it even more. You forget, that you may have people out there...the ones that's out there like that, they have a couple issues, not just the substance abuse issue but probably a mental health issue also you know. And making someone doing something like that and they're out there on the streets and uh...

It's not helping.

Yeah, it's not helping and they're...they're on the streets anyway. So, I don't know. I don't know. And it got to be, I believe that it has to be...a lotta people that are out there on the streets is because they homeless, or stuff like that. I mean and you got to do what you got to do to survive. And uh, I don't know.

Incentivized testing, give them \$5 or gift certificate, movie ticket?

Ummm...it's...I mean it's...it's not a bad gesture to see. It's not a bad gesture to see well look here...tickets to a movie or tickets to a basketball game or something like that. Tickets for testing, to get tested, if it's confidential. Um, but uh...but the thing is too is that you got to make sure that you have the right uh contact person. If you got the right contact information uh after you do it. You know? You don't want to go out there say well here we got free basketball tickets, we'll compliment you basketball tickets for you to get tested. And they go out there and they put in the wrong address. Give you the right name, put the wrong address or something like that. And then, if they are positive, how are you going to get in contact with them? That's something that you got to really think about, you know. I mean that's a good idea, but then you got to look at the flip coin about it. You know cause some people may use somebody's, they may use people's address but they may not be living there. You know, they on the street. But they use the people's address, that's where they was at. That's the thing you got to look at. I mean, they..you'll get the test but after you find out they're positive and you got your survey as far as finding how many people are infected, but how are you going to get them to come in for treatment, how are you going to get them to come in for counseling if you don't have the right contact information?

Fair to have to pay them to come in to test?

No, I don't think it's fair but I think it's a good...a good...um. It's not fair, but life isn't fair either. You got something...it's a lot of things that's not right [laughs] you know. But is it a good gesture? Yes. Is it something positive that they could do? I mean shoot they give out tickets for anything else you

know, and it's something that isn't even worth your life you know? But something like this, yes, I think that...now that I think about it yes I do think that it's something to think about. But like I said, if you gonna do it, you gotta have two things. One, make sure the contact I guess. And the two is, how you gonna deal with the person if you can get the rapid read...like...the rapid um...umm..the rapid test...

The oral swab?

Yeah, the rapid testing and yeah and then you give the tickets, and then you find out that if they're negative or positive right then and there, how are you going to deal with the counseling? You know? What's the...how are you going to deal with that? I mean...right then right after you get the test. And then they leave, you don't know what's the...they going through some things now. Specially if they're homeless.

So you want to make sure after you get the test...

After they get the test they get the counseling, where they gonna...how they going to deal with life after that. Um, uh, is there uh, will you stay in contact with these people. Um, it's not just oh we just gonna do the survey, no. We want to know...we care about you. We want to help you.

SO make sure know where they're going and treatment.

And follow-ups. I would look into maybe follow-ups on you know. Is there...and if they are...what can we do to help these kinds of people, you know. Um. I think that uh, I don't know. Now that I think about it, what type of facilities that we have for just...these types of people. Not like far as...see thing that gets me is that they have a facility out here uh, matter of fact...uh, that just deals with people who...housing for people who have AIDS that just about ready to die I guess. You know. And, I think that that is so much like of a discrimination for people who are just HIV+ and they're on the streets, and they don't have no facility for something like that. You know. You got to be damned near dead for you to go into one of these facilities that you can go in...and...and...you have housing for these types of people, but you don't have housing for nothing...for people who are living with the virus and they're...and they're not that sick you know, they just struggling because they don't have the income to really, really take care of themselves right now. If you on public assistance, they're not helping you because that little, that little thing that they give you, that little 102 dollars is not enough to get you...get you stable to be independent. You know so, what is it that um...what is it that you can offer people like us? You know? What type of housing can you...what type of low income housing that you could do for people who are HIV+? You know, you got people out there, you got the system for women and children, you know. And uh, I really think that it's something that needs to be thought about.

So in addition to testing, what to do with these people after they find out they're positive and resources.

Resources, yes. Yes.

So definitely not mandatory because you want to respect....

No...no... you want to gain their trust, you don't want to just be forced. I really...that would just make them run away even more. Or, I'm not going to no hospital, they want to...they want to test you for all that...no no. I think that just forcing them no. it should be voluntarily. But if you gonna do somethings, if you're going to uh, uh, if it's going to be that way then like I said that some type of way that could get passed just say they don't care as far as people make it mandatory and do it anyways. Then I suggest that they do some things for them. Not just force them to do something

that...leave them out there. You know. You supposed to be doing something for them. Make sure uh, and do follow-ups don't just leave...leave them hanging you know. Because if you force them, and then they turn out to be positive, then and then you leave them...what you do...you just done destruct somebody's life. And who knows how they'll deal with it. You know, they go out there and say oh well hell with it...screw somebody and pass it on. You know? And you got people out there that's like that. There are people out there that's like that. So I really believe that. You really got to be considerate, really, really considerate and show that you really care about people who are positive. You know, who has this virus, and and work with us. You know, I mean as far as the testing wise, I think that, I think that you really got to, however they come up with it you know, I mean the suggestions is good. Yeah, sure why not come get the tickets... but like I said make sure that you got the resources and everything, and be prepared to deal with it because it's going to be a whole lot of people out there that have, that's going to fly off, you know. That don't know how...that's not going to...especially if they don't got no family.

So if we offer incentives, we also have to be prepared to offer resources?

And, and make sure to have someone on site.

Follow ups

Yeah, follow ups yes and have some type of place for them to go. Because you may have some that's on the streets you know. And uh, have some place that's on the street. They living on the streets, have some place for them. That's...I know that's a lot, that's a lot. But I think that it would also show that you care about them. And that person would feel some type of...how you say... some type of way that they care that somebody care. And then maybe they would care enough that they wouldn't go out there and pass it on to somebody else. You know, because some people they would say oh well I got it and then they threw me out there and I don't care. I'm going to go out there and I'm just going to give it to everybody. I got it, now, so so what because they didn't care about me. They didn't care about me and they gave it to me and didn't let me know, so why I gotta go tell somebody else? You gotta think like that. It was done to me, but only thing was through the grace of God that I haven't thought that way. I haven't felt htat way. You know, I thought as far I was going to die, yeah. I thought life was over. I still sometimes think life was over, you know. Because I want companionship you know.

Demographics

43, male, African American, public insurance, below \$20,000, high school, unemployed.

Subject #004

When were you first tested?

1984

What happened that made you go get tested?

Well, I shot drugs, IV drug use, and I don't know. I went to the county jail and broke out in a rash. It wasn't a regular rash like you could itch or scratch. Or scratch an itch, whatever you say, however you say it [laughs]. But uh, you couldn't like get to this itch, so it was really bothering me I was like going nuts. So I went to the doctor and he said do you use IV drugs, I said yeah. So he says it's mandatory that we test you then. I was on drugs, so I guess they had mandatory testing for IV drug users, so I said I was an IV drug user. He tested me, and he said it'll be a couple weeks. He took like 3 tubes of blood outta me. They call me back down, and it was like two guys on the bench before me. And they went in, the door stayed open and he came out. And the other guy went in the door stayed open and he came out. Then I went in and he shut the door. My heart jumped up into my throat because I knew. If he's shutting the door he wants to tell me something he don't want nobody else in the jail to hear. So he tells me I'm positive. I don't know, I was like in shock I guess. I wasn't expecting nothing like that. It was like a death sentence. So I went back to my cell, and I guess...I like really was in shock. When I went back to my cell, I started crying and I prayed to God. And I said God, I can't deal with this. Just the worrying alone will kill me. Take this disease from me I mean. He took it I guess.

So it was the rash that concerned you and they had you tested for you for that because you went to the doctors in the jail?

Plus, I... what it was 1980, this guy Sandy was over at this girl's house I was at. And he was doing Dilaudid. I don't know if you've ever heard of Dilaudid? It's like morphine, synthetic morphine, it's a little pill. Anyway, he was doing that and he did like 8 of them. A half one is enough for you. He did like 8 of them. So he..after he got done...you know what a cooker is? You gotta put heat on...so you put in like a lid or something or a spoon and he had them in there. And he goes, after he was finished, he goes here there's a whole lot in there you want it? So I said yeah. So I said do you got a set of works you know, a needle? He said yeah I do, but I got AIDS. And I said I don't care. And I used it. So when I got the rash, I put two and two together yeah so you know...

Was that first time tested?

Yeah, 1984.

After you got test result back, any care? See a doctor?

Uh, yeah, well...they kept asking me if I wanted AZT they said it would prolong my life. And I said no. They said why not. I said because there's as much that you know about this disease that you don't know, and I don't want to be no guinea pig. And as long as I'm not hurt or hurting or sick, I don't want it. So, for a lotta years I said no to that. And then, when I went to north Hampton county jail, the doctor, he knew me from times before, but he called me down he said listen, your t cell count is 30. He said 200, you're full blown aids. He said, 30 you're...you're lucky you're not dead right now. I was still fighting off colds and stuff I didn't know what was wrong. So he says if you want, he goes, when in 1984 was killing people, you were right, he was like how did you know not to take this. God told me this. A little secret for anybody. He said before you make this decision, make sure you're going to be responsible, because once you start taking medicine, you have to keep taking it you can't miss doses or else you'll become resistant to it. So I said okay. I said no, I said let me go back to

my cell and think about it. And this guy comes out of nowhere, and he says. There's a guy he's in a house there's a real bad rain and it starts flooding the street. And it comes up to the first floor, he goes up on the second floor. Comes up there, he climbs up on the roof. The water's still coming up, so he's climbing up the chimney and the antennae. And here comes a little rowboat thing. And the people were yelling yo you need help we've got room for one more. I said no I believe in God and God's going to...this is what the guy was saying to me he says no I believe in God, God's going to save me. So they rowed away. About 5 minutes later a helicopter comes by and dropped a ladder. He says you need help? We got room for one more. I says no it's alright. I believe in God and God's going to save me. So he left. And the storm you know drowned me and I died and I went to heaven. And when I went to heaven I seen God, and I said hey why you let me drown I believed in you. He said look I sent a rowboat and a helicopter what more do you want me to do? So that made me think that He sent this doctor to help me so I trusted him. I went down and I told him yeah I'll take it, and I started taking it. That was about 1999 I guess.

So 1999 is when you started treatment?

Right. And uh, my viral load it was in the millions, and now it's undetectable, and my t-cell counts are pretty high too. I think it's about 450 or 500.

When you got tested, did they tell you anything about what it meant to test positive? Any counseling?

Uh uh, I was in prison.

So they just tested you, did they tell you anything about the disease?

No, I knew. They had studies that you went to, but nothing specifically for me or for a group of...they didn't want to single nobody out in prison because it's not a good thing. But if I became friends with some guy, I told them. Because I thought that they should know. Like if you want to be my friend, there's stuff you need to know before you make this decision rather than get into a friendship with somebody and tell them and then it's like ah I can't you know. Then you miss them.

So no counseling...

Yeah, no therapy, no counseling. I never had any counseling at all ever. I did my own research. Well that and what my doctor tells me.

What motivates you to do your own research?

Umm...you know what it is, I'll tell you the truth. A hundred people have the AIDS, what do you think 90 of them are? Homosexuals. I'm not, so I don't want to be in support groups...I don't like being propositioned by men. I mean, yeah...it really doesn't...it does bother me I guess, but it don't because I can say no. But uh I don' know, I just don't want to be in a category. It's probably wrong for me to think this way. Like stereotyping.

No, I mean you are entitled to your own opinion and everything.

Yeah, my own opinion.

So this is why you do your own research, because you don't feel comfortable in support groups and things like that?

No, don't feel comfortable. But I mean, I don't have no problem talking...I'll go out on the street right now and yell...my sickness. I have no...embarrassment, no shame. I mean I was proud enough to stick the needle in my arm why should I be ashamed of what I got behind it?

Changes in testing recommendations. Explained VCT, opt-out, what changes were.

Mmm...do you have to tell them?

I don't understand what you mean.

Do you have to tell the patient that's being tested?

Yes, so like I said the doctor treats the HIV test like any routine test like for cholesterol...

Then I think it should be mandatory. Cause I think that if it's not mandatory some people will not do it out of fear of finding out maybe, and out of fear of someone else finding out. That's just my opinion. I mean I don't have those fears but.

Do you think it's fair to make people test?

Yeah why not? Why shouldn't you know you're...you know...like.

People may say that it interferes with right to choose.

Well let me ask you a question now. Say I have sex with a girl. And I don't know I have AIDS and I give it to her, right. Can I still be charged with attempted murder? No, right? I have to know I have it. So see that right there is a deterrence for some people. You see what I'm saying. So that's why it should be mandatory. Should have no choice. Swab goes into your mouth, it gets tested, and you get told whether your negative or your positive.

How make people take the test?

Like they subpoena you to jury duties.

What about paying people to get tested? Gift certificates?

Oh paying? No. you'll probably get a bunch of people who don't have it that just want the money, and ain't worried about their rep because they're negative. Mandatory will test everybody though, and there won't be no money. The money that you'd save on giving gift certificates and gifts for them to test, you can test everybody.

How pass through something like mandatory?

Just the next time they go to the doctor they get tested. Even if you didn't mail them something to go to the doctors. Or maybe in the papers.

What do you mean?

Well that wouldn't be mandatory now. Yeah, just at their next doctor's appointment. But I think it should be a mandatory test. I mean who would you hide it from? Who would anybody hide it from?

So mandatory is best way?

Yeah. It's like, when you go through a metal detector, is it forcing me to take my weapon out and throw it away? Can we look at it that way? You're forcing me to get rid of my 9mm. why are you doing that? I don't even have no right to carry a 9mm. so the metal detector is like that.

So you're saying have people at next doctor's appointment get tested. What about people who don't go to the doctors?

I guess they'll slip through a loophole. But you're going to have that. You can't have everybody. Just the people that fall into categories be tested. Drug users, prostitutes, guys who sleep around a lot

and don't wear protection. I've never had protected sex in my life. Never gave it to nobody. Never been sick neither. Never.

So do you think it should be anonymous mandatory testing?

No the person should know. You have to tell the person. Anonymous if they're negative yeah.

Explanation of anonymous vs. confidential testing, what confidential is, is it fair?

Well yeah, because you're a killer if you have AIDS and you don't know it. And you're just...

More important to protect people's health?

Yeah. By doing that to a person with ADIS you're protecting other people by telling him that he has AIDS and don't be doing what you've been doing because you're going to kill all these people or, make them sick too.

Do you think that picks on people with AIDS?

Picking on them...no. Just let them know. I don't know. Just let them know that you can hurt somebody with what they have so be careful. If they didn't even know. Because I think without knowing, I don't think there's anything that anybody can do if you gave it to 10 people and they died. But if you knew, if you were tested and marked in a book as tested positive like me, go to jail for attempted murder.

Help reduce fear related with this disease?

No, it just let's everyone know where there at.

Motivation to change to opt-out is because they think many people don't get tested because they're scared of the disease. Do you think mandatory would be good at doing that?

I guess...maybe mandatory ain't good. I see what you're saying about how are we going to get them in there. It would be hard. And their doctor's not an aids doctor so they probably wouldn't have the equipment to test them.

No, they would. Oral swab available, quick test results. Now we're trying to see how do we just even get people to come in.

Have a mandatory in the hospital. I think that would help. Because eventually everyone's going to wind up in the hospital in the emergency room for a little cut that needs stitches or a broken bone.

So if they go into a hospital they have to get tested.

Hospital is mandatory, prison is mandatory, county jail is mandatory. The minute you walk in you get tested. Yeah you get tested for everything else too.

Will this make people not want to go to the hospital?

No...no. I wouldn't get mad at you for telling me my nose was on the back of my head and I needed to put it over here. Why would I get mad? I would be glad you told me. Cause if I didn't know...I don't think it would deter. I think maybe if you snuck, you'd get them mad like you violated their rights.

So if we told everyone that it's a law now.

Yeah, and the doctor said that before I check out your illness, there's some mandatory testing that we have to do to you. It was like that in prison when I was there in 1984. It was mandatory. But that's in Jersey. And I guess it was when you either when you went into an institution, a hospital.

So taking what they're doing in prisons into hospitals?

Yeah.

Example of other mandatory testing laws.

Prison and jails you're going to find the most people with it, I think. Walking through them doors. I don't think too many guys go out and pick up a prostitute and wind up with aids. I don't believe it.

To make sure I have this correct, paying people not as effective as mandatory in getting people to test?

Right.

Ever a certain amount of money that would make it effective?

I don't know. Who's going to pay it?

Government?

I don't know about that. Maybe Obama will pay for it.

Just to wrap up, what about opt-out?

What's opt-out again?

Explained opt-out.

Isn't that just like mandatory?

A little bit. But they have the choice to say no.

You do mandatory too don't you? What do they handcuff you?

Example of pregnant women mandatory testing.

How about for me if I went into the hospital right now and they had mandatory testing, and I had a broken bone. And they said to me, before you see a doctor you got to take this test, and I ask what is this test for, and he says AIDS. And I say no I don't want to take the test and I leave the hospital with my broken arm and stitch my own cuts or whatever. Maybe on the news, say it or whatever? Because it is tricky like that. Mandatory's not...you're going to have people who hide and don't want to have it done. Look at how many who will get it done. Decrease the percentage of people running around who don't know.

Demographics

51, male, white, uninsured, below \$20,000, completed less than 10th grade, unemployed.

Patient 005

Interviewer: Circumstances when first tested

Patient 005: I was shocked. I had no words. It's like how, why, how, when? I was trying to refer back how do they get it.

Did you first find out here or from your home country?

From my home country. I was feeling sick, I wasn't feeling so well so I went to the doctor to find out what was wrong. Because I was feeling weak, lost appetite, and they do check, I'm okay nothing is wrong. I said just test everything do whatever. And I was lucky I was a volunteer I used to work with an organization that help people, red cross and stuff. At least I had an advantage of seeing doctors and that's how I found out I was HIV positive.

So when you got your results how did you feel?

Sad definitely, sad and withdrawn. And then I just buried myself in programs in getting people how to you know, be safe... encouraging people to get tested. But it was so hard to get people to participate, especially back home it was regarded as... nobody wanted to accept the illness, it was like a taboo. Because people who would be found HIV positive, because they didn't have the medicine that worked, people were degenerated, the illness, the side effects were so terrible. People died so fast, because no medicine, it was terrible, really terrible. You see a whole family... And you know back home, for us it's not like here one wife one husband, you could find maybe a husband has four wives so you can imagine, and all those children dying, individuals staying without parents. And some of them born with the disease. You find maybe 12 y/o looking after 3 y/o. Their home is different, here I see people are lucky. I find it so hard when some don't want to accept treatment or volunteer. For us back home you want to run and beg for the save, but we can't get it. And here, people don't want it. And that's the difference. I wonder why not. Maybe because they haven't witnessed people who are suffering. To see how they suffer. Because here they have their medicine, they haven't really seen the side effects of it. Maybe to encourage children to visit hospitals where people are suffering and then maybe they will understand. And especially us mothers. You listen to your kids. You know kids are not like long ago where you are scared to sass your parents. But when they study and know the reality, and they're talking about it at home. Maybe at the dinner table or something. That's the way you pass messages to us.

How long ago was it when you got tested?

In 1978.

Did you receive pre/post test counseling?

For us we didn't have any when we came here. When I was positive, then I came here immediately with my sister because for them they were already here. I never wanted to come here, I preferred to stay home. But because of the medicine the travel, I decided to come. My intention was not to stay here. Was to stay and then go home. But then when I got here, I got more sick. I diagnosed with another type of disease. Gan barre syndrome, something with nerves [*I think she meant Guillain-Barre syndrome*]. It's nothing to do with AIDS, so it's a different kind of disease. So now like two

things at once. With this Guillain-Barre, when I got it, my organs almost all of them failed. My kidneys.. in fact I was on dialysis for some time. Then I started relapsing. That's why I couldn't go back home. Because the area we were staying we didn't even have dialysis machine. So if I was there, I would have been dead by now. That's why for me it's a blessing being here. And here everybody was nice. Sometimes my family they couldn't afford it. And then I was not working, but I got help from here, people help. No questioning. Everybody was nice. Free counseling. So for me, I consider myself lucky and blessed.

How long did it take for you to come to terms with your diagnosis?

You know the funny part, I got over it so fast because I got to know it first before.

Yeah, because I was learning, I was involved in it. Plus where I was working, they had started spreading the news. Because that's when there was a village that was wiped out completely. So you know. The country I come from, for us we accepted it so fast not like in Kenya they didn't want to accept that the disease was here. You know that some belief that it is a curse, you know that kind of primitive you know. But for me, the country accepted it so fast that everybody got involved so much especially when one village got wiped out. Only kids you see, the whole village no people, just kids. So everybody got involved so fast, and that's why you see for us it's just like normal other diseases. Just the problem is getting the medicine.

Where is home for you again?

My home is in Uganda. Yeah. But yeah I was involved in it. Safe sex, used to go to schools distributing you know in high schools trying to educate everybody. So I considered myself at least knowing. And you know the way I contracted it was through helping. It was during the war, there was kids that were injured they needed the transfusions that's how I got it. I was helping and then I got sick. Because at first we didn't know with the certain safe ways, the needles, blood transfusions you might be giving straight to straight. Because I was a universal donor so yeah. When I see a kid suffering I would just go... yeah. That's how I got here because everybody you know someone helping someone else. When I came here the system started changing. Trouble, no money, no medicine sometime they run out of medicine. But here and there I get some.

Changes in testing initiatives in the US. VCT to opt-out

Yeah. The routine one would be you know. It would be easier and faster. It's just like going to the doctor for normal treatment and they find that oh if you accept to be tested for everything. What's wrong with that? If we get to know earlier the better than learning it maybe when you've already gone to AIDS than being positive. You know the difference. If you know that you're positive then you start the medication and get rid of it faster than knowing it when you are really already sick and they test you and you already aids. Yeah, I think I prefer this, just to make it normal routine to encourage people to do it every, just you go normally... like dental you have to go every 6 months. Why not go for general check up every... and you know to teach people. Why start uh.. sexual when your partner you don't know. Because if you love each other and you all tested, then you won't be sick. It's education and volunteer. Not like me, just helping, just because I felt sick and just wanted to check everything. That's how I got to know, that's how I got lucky. Because for me I've always been undetected. Because I learned it early, and I'm doing okay. Not sick, just for general check up.

So what do you think about taking away the paperwork?

My opinion is people should be allowed to consent, you can't force people to do what they don't want. The legal stuff... you explain to them but just to encourage them to make it as usual. People are different, I can't force you to do what you don't want to do, but I don't see anything wrong with it just general routine and being checked everywhere.

Just to summarize you feel it will help getting more people get tested.

I'm sure it will help. It will work. It will encourage people.

Incentivized testing as a more recent development. How do you think it would compare to opt out?

Yeah, it will help. It will help.

Do you think there is a certain type of incentive that will help? Money versus gift to grocery store?

Gift certificate

Specific place?

Groceries, just small items. Yeah, small, small items. You don't want to encourage too much. It's just like advertising. Yeah, encouraging people. You are helping them, but at the same time you are educating them.

So why grocery store?

Other places, people will just take advantage of it. Other people will take it just because it is a gift, not necessarily going to do it. People are different. I don't know how to put it. But some people will take it but not take the test.

Receive gift certificate after complete test.

Ah okay. After you do it is when you get the gift. Then maybe that will encourage them. And then you know... because people having difficulty getting food. So that's why I'm saying groceries. People will come more here. Ok so also maybe depending... also when maybe it is cold, groceries will be... or maybe meals after. So you say like today will be free meals after they do test. And while they're eating you educate them. Or you know. Outcomes. Or if you hear someone has it, how to prevent it, you know.

Any specific dollar amount?

Just a plate of food is more than enough. Because it's like you're taking their blood, at least their benefitting, it would be negative or positive. Then they eat food, and they make up what you took away.

So groceries.

And maybe when do we meet, it should be...people come from far. It should be like area where they can transport where it is easy like location.... So you choose like...today we do it at this school, certain neighborhoods. Because you don't want people to come from so far then they spend... that will create complications for them to come. Just say one location today, we do advertisement, we do free meals.

Mandatory testing. Seen in Connecticut and pregnant women, federal prisons.

I think it is good especially for pregnant women.

Is it fair?

I think it is fair

Why is that?

Because you are not doing any harm to anybody. It's not like DNA or whatever. It's just a decision you want to find out if you have a disease. But as you said, I think it depends on the individual. For me it would be okay. But for some people they would want to consent. I think that's when it would come in. I don't think everybody would agree to that.

So do you think mandatory would help increase numbers?

Yeah it would increase, but not sure if people would agree.

Fair to make people get tested even if they don't want to?

No, I don't think it is. Because some people will think it's like violating. You can just explain to them the benefits. But if person doesn't want to, you can't force. You just let them make their mind.

Any instance of mandatory that would work/ be helpful?

I was thinking of someone coming to foreign country traveling from another country, it should be mandatory. Whether it should be a law, you have to do it.

So regardless entering or leaving a country, just if you're traveling.

Yeah, that will work. And people will want to do it.

Why is that?

Because you... you'll be helping. In a way I don't know if it is a good thing or a bad thing. [laughter] But they'll do it because you want to travel. But I don't think it is fair [laughter]. It will help with census, knowing how many people have AIDS, how many are positive, how many... you know. That's the way to keep statistics about health.

Demographics

41, female, African, uninsured, dependent on family (income \$20,000-\$50,000), college educated, unemployed

No additional questions or comments.

Subject #006, nickname Joe

Introductory statements, overview of what will be discussed during today's interview.

Circumstances when first tested

I was tested in Chicago, and I had just gotten divorced, and I was kind of in my bi-state, and was going back and forth between guys and girls, and when I did that I would not only do an HIV test but also do a full panel work, HPV, the HSV, the Chlamydia, gonorrhea, syphilis, I did all that stuff which cost \$700, which is how I know when people say they're drug disease free, that you're probably not because I know how much it costs to test to check all that.

Why did you decide to do all these tests?

It was more to see if I was okay, but I just didn't want to pass anything along to anybody, especially from when I was dating women, because I know that it would... well it's my... at least it's probably true but I guess my thought was at the time there was more risk on the sex with men than there is with women, and I didn't want to be... if I... wanted to make sure I didn't pick up anything from men then pass it along.

Very first time tested

It was probably... let's see... since I started having sex with guys only in the last 7 years so it was probably I did it a couple times, so probably 2001. But that's about the time and it was probably within 6 months that I kind of had any involvement with a guy.

What made you want to get tested the first time?

Kind of the same question. Well, I was involved with a guy, and then I was going to get involved with a woman, and before I got involved with her on a physical level I wanted to make sure I didn't have anything I could pass on to her.

Confidential or anonymous?

I had it done at a clinic so I guess... I mean they knew who I was since my doctor did it.

Any difficulties?

No on that one. I mean, I went to a clinic you know and I paid for it out of my own pocket and I paid for it with my own insurance I didn't want people to know about it and have it get back to my company. So from that aspect I guess you could say yes. But I went to a clinic which was kind of off the books and just paid for everything

Concern about confidentiality

Yes. Well confidentiality even what the test was.

Elaborate about concerns had about test and results

Um.. I wasn't out at the time, so I didn't want to tell the nurses. So I just told them I wanted to do a test for any STDs and HIV is just part of the test I mean I wasn't concerned about having it at that point, so to be honest I don't even know... it's like I haven't really even had any what I call sex-sex. Anal sex we call sex-sex otherwise..oh... it's just sex but not sex-sex. Umm... So I guess it was just

more from not wanting people to know about my personal world. It was more about the gay thing than the actual test.

How did you feel about your test result?

[laughter] how did I feel? [laughter]

How did it impact you?

Significantly. That result came here actually, and I did do an anonymous test on that one. And what led to that test, because once I moved back from Chicago, actually I always played safe so... I didn't get tested, and I tested negative last time so I just always... knew I was negative. Well, I had an experience here... well I guess it was 2006... but what had happened, I had been involved with a guy from New York I met with him and he had told me he had tested positive, but not to worry because he um you know found out there was someone who did not disclose to him. That's where he got it from, and the odds of me having it were slim. So through a friend I found out because it's like well where did you get tested in Philadelphia and he told me about this place you can get it done anonymous, which I did the anonymous, the rapid test where you find out but it was done with blood and not the swab. And uh, so I did it and I actually didn't expect... I expected it to go fine until I was waiting it to process when he told me the symptoms when people seroconvert, what happens to them and I immediately thought to a year and a half earlier when I had been sick and actually went to the hospital but I attributed it to some... stuff... medical stuff... that my... was in my family. So... and the test came back positive. And that was the last time I got tested.

How did the result make you feel? I know you had said that it impacted you significantly.

Um... yeah it's like... oh my god what's going to happen because it's like I was still struggling as a gay man coming to terms with who I was with that, and now I got hit with a double whammy and there is a huge stigma, which goes to why I think people don't get tested, there's a huge stigma not only in society in general but the gay community which should be much more understanding and aware of HIV, there's a big stigma in the HIV... the... HIV as a stigma in the gay community as well. So it was just that all of a sudden you feel... like a leper. It's like you're leprosy and you don't have sex. And then it's like ooh it's me and you feel like you're in this... you're isolated and it's like "woe is me" and I'm in this world that isn't supposed to happen to me and... which I'm sure everyone feels like it can't happen to me. And I immediately knew. So after that, then I knew who the person was and within that next week I went to find him... he was down in Florida but his grandmother whatever who was... watch him kind of confirmed... everything became unraveled about the truth about him... he was a sociopath but... we were, I was in Chicago, he was here. And I didn't quite... He told enough truths that kind of made him believable. But uh ... at the end of the day I made the choice. My...my... thing I was upset about ... in knowing now.... Now knowing what I know now I said first of all how could you, you know, lie? I can understand why guys who are positive lie, um, but I also think that he put me in a position where he put me at significant risk and I wasn't given the choice and uh, had he been on meds or whatever... you know, been taking them all, my risk would have been reduced, that would probably be okay but I don't know if I would have gone out with him... but maybe if he was positive at the time I probably wouldn't have, but at least if he had been safe I would have been okay. So the fact that he pushed for it I didn't push for it, and he insisted he was negative when he wasn't and then when he wasn't on meds and he had a viral load and that was kind of unconscionable. If he were still in Florida and we were floridal...of course there it's against the law I don't know about here. But I was... Again I was in a situation where I'm not going to push the envelope and I bared some of the responsibility.

Difference in stigma between the gay community and everyone else. Expand a little more on what you mean by stigma and things like that?

A stigma would mean.... There's a.... I say uh... people would say in the mainstream that gays are accepted. The reality is people... the majority they respect them in some ways you know there are still the jokes and stuff that go around. So in the mainstream society in the US there's a stigma to being gay. A lot of gay prejudice comes with who they are, there's a lot of people in the mainstream that have been accepting of them but there's still a big contingency that's not... and the church probably has a lot to do with that, what people are trained what they believe, so it's the..you know...the church and then you get the you know the whacko skin heads and everyone else but there's... and ... so there's still a little stigma to being gay. There's a lot of people who are gay that are not out. The number of people are... a lot of people that bore that cross that made it easier for a lot of people coming out today. But you still see kids that are. They say they're gay and their family throws them out. Cut them off from all financial things which doesn't do much for their mental health aside from a lot of other things. But so there's still stigma and.. when I translate the stigma that you see from the mainstream to the gay community, I translate that same stigma from the gay community to HIV. The gay community is kinda.. they're...it's...it's...they don't need a lot of people outside the gay community because it seems they're all packing each other from within but when someone becomes positive, they're kinda like outcasts, they're looked on as dirty and looked down and to be honest with you there are a number of positive guys that are reflective of that. They become positive because of the lifestyles they choose. They want unprotected sex, they want lots of sex with lots of people, and you know, in their right they're just into a lot of different things.. so it's just, and they know it's just a consequence of their actions. I also know a lot of people that acquired it...they're into drugs, they're addicted to drugs and you know to alcohol or whatever which is why they have a lot of problems with people staying on their meds because of their addictions and they don't kind of have it. I'm.. I don't know what the percentage is, I know I'm not the only one in my situation I know there's people who have been in relationships people who have cheated brought it back into a relationship but there are number of people that were... thought they were taking precautions, thought they were with people that they trusted and you know they were misled. So now you know you kinda have it so you're thrown into that. Well, I choose not to be... I kinda have been withdrawn from... I'm very private about my status. There's people that are out they tell people they're positive and they're cool about it. And they're kinda in my way they're leading the charge with HIV like the gay men led the charge with it's okay to be gay 20 years ago. So in essence the HIV positive movement is where the gays were in the 80s.

So why do you think this stigma exists?

Fear and lack of knowledge.

Lack of knowledge..?

Lack of knowledge and the fear... the fear is because they... once you're positive people drop you like a plague, you're a pariah. People... I've talked to a guy that works for the FBI, was positive would never have thought it'd happen with him his partner cheated on him and he found out. His friends, they all like bailed on him. So a number of them... and then people say oh that won't be his friends well these are guys he's hung out with for 5, 6, 10 years, and some of them have come back around and he told me that some admitted they had been playing unprotected so all of a sudden they were afraid what would happen but it's..it's a fear of it and then some other people just don't want to be associated because some think oh well they're associated with someone who's positive and people know and people are going to think I'm positive. And they kind of back out, and the...the...thing I think is the fear is the people don't understand it. I think a lot of people in the gay community still

think it's a death sentence. They think if someone's positive, they think like if you're around them they can catch it. They think it's like leprosy if someone touches me I can get it, and it's not... which is nowhere near the case. It's my understanding that a lot, and you may know this more and that's what I was going to ask the doctor if it comes up, that there's more cases... well the case of HIV is people who really truly think they're negative, they're out screwing around and it's happening in clusters, and all these people think they're negative and having unprotected sex and are getting it or it's you know it's positive guys who are lying who aren't on meds that are having unprotected sex and passing it around.

CDC stats on half of all new infections caused by those who don't know they're positive. One out of 5 positive guys don't know they're positive.

Okay that half are coming from people who don't know... Because I was told, because being on meds and being undetectable, even if they're having unprotected sex which happens a lot with positive and negative couples in the gay community, there's been no known incidence of someone who's been undetectable that has transmitted the HIV to someone who is negative even in unprotected sex situations, which I'm told a lot of doctors don't want to talk about that and give that, but they said anything. And I talked to one doctor about this whole study that there's been no known cases of HIV passing for someone who has a viral load less than 1000. Which means it's being transmitted by people who think they're negative. People think they're negative they're not treated they recently convert they can be in the hundreds of thousands, their viral load is extremely contagious. And then you have the others who aren't on meds that are floating in the 15-20,000 range whatever where their t cell count is high but in they're the mind with the doctors who say oh you should wait before you go on it.

Don't have any numbers. Talk to doctor about it.

We're good, but that's the kind of take. But there is definitely a stigma, and there's this fall out. I've been with guys and you want to talk and get a feel for them before you share because there's a risk factor you don't know who they're going to tell and how people, you're perceived in a different way. And uh, I kind of take it... but what their sense is. It's kind of like you know I grew up in the suburbs, and all white. So when you watch you know every once in a while as I grew up there were times when I was uncomfortable you know when you get around African Americans. And when I was in certain neighborhoods I'd feel very uncomfortable. Well why is that? And I think part of that is because of my conditioning I saw on tv and the only thing you would see is the news and they're only talking about the bad things they don't talk about the good things that happen, and that's part of the news fault. I remember there was a black awards ceremony where they, just the achievers in the community and doing things and it was on page 32 of the newspaper, it didn't get covered by the news media and it's stuff like that, it's what we... you know you kind of think. And the gay thing it's just that stigma it's what you don't know and you're afraid and when someone has like... well I'm going to stay away. And it's a very.. it's very real and its uh.. very hard. And I think if...if... people become more understanding... and become more educated and people of all ages are not very educated on the subject. I've only learned and got more educated I mean I had to get educated because since it's like now I have it you want to deal with it you need to understand it and I need to understand it with relation to other people and uh... because I really don't want to pass it along and uh... there you go.

Pre post test counseling?

They gave me places where I could go. Uh there was this one ...mazzoni center is one here and there was another place. And I actually called, there were two friends of mine that I told. When they

knew. one of my friends told me I should call this guy who's a friend of his that was involved with the aids of Delaware. He didn't tell me that guy was positive, which that guy told me when I called him but he referred me to Dr. Short who is here, and uh.. that's how I got over here because I went on a recommendation and... he'd talked about doing some counseling stuff but at this point I haven't.

Before test, prevention testing.

Oh before the test. After when I got the test when they knew I was positive and they told me... I guess they probably gave me stuff for where you could go to get counseling. I remember a sheet of paperwork, different places on it.. and uh.. of course with your tester before it's all about prevention, different types of contraceptives and stuff like that there's literature all over the place.

Treatment immediately after found positive?

Oh once I found out I had to...I had to find... you know I was getting a doctor and I got a doctor... this was December and they couldn't get an appointment until the end of January, I think it was sometime in January. But I went to get blood work done ahead of time because I didn't want to wait so they agreed to have me come in and get blood work. And they called me a week after and told me I needed to come in because apparently see I had known it had been in my system for a year and a half and the count was pretty low and stuff so they brought me in. and of course I was sitting here and I was reading a board somewhat like that chart one of those charts HIV charts. I'm looking at this and it's like well from that chart and based on the numbers you're telling me I should be dead. So... and that's when I learned from t-cell counts that you can be anywhere from 500 to 1500 and be normal and be healthy so there's lots of differences. So I did start meds for me after I found out it was pretty quickly... because they found out it was... Dec 13th 2006, so by January I was on meds. My doctor was the one they felt that my cd4 count was at a level where I should go on meds right away.

CDC changes in testing recommendations, explained opt-out vs VCT.

Okay, I have a question then. What... how many people are specifically opting out not to be tested for HIV?

Study done in ER, 90% receptive to opt-out testing, if physician initiates, people accept.

Because my first thought is anyone that would opt-out of.... not wanting to be testing for HIV is someone that needs to be tested for HIV. And...and that goes right to the point why... and that goes right back to... why just from a personal health standpoint you should know. But in... but I think it goes... I was just curious about that because there should be no.... [laughs]....if someone opts out it should be mandatory at that point that they get tested.

What do you mean by the type of person who needs to test are the ones who opt out?

They opt out. Yeah because I know the people who you're talking about... it's increasing and it's increasing 5 times. Well why is that? It's because people are carrying it. And I think you said that if 15% people think they're negative and you know there's 20% of the positive community who's not aware they're positive, there's a reason they're not aware. They don't want to be aware as long as they feel okay, they're not going to say anything because of the stigma. Because they don't know. And that's why people stop taking their meds, they don't take meds because they feel okay. They stop taking their meds and they wind up dead.

Misconception that if feel okay you're fine

Yeah, and there's a misconception of that. I think the bigger issue is once you know, you can't tell people you're negative anymore. Well, you can but from a conscience standpoint, in good conscience it changes the game for you. So in the gay community if you're sexually active, um, you know ...you, being negative you get a lot more action. So we're saying, but once you know, people know and all your friends are negative and everyone's in this little clique and these groups, and these cliques and these groups look down significantly on positive people and they're looked at as dirty and unclean and you know the... just you know the big faggots and was their own fault that they did it and they had it, you know, coming to them and so when you have all the people in the mainstream gay community that feel that way, there's no way in hell [laughs] that you want them to know that you want to have it or know. So if you're having unprotected sex well it's like you really don't want to get tested because you're afraid of like well what if... it's the fall out and you're thinking well you know hey as long as I'm... and that's where I think hey as long as you're feeling okay it's like I'm not going to get tested it's like I'm negative, I'm not showing anything. And to give you an idea just how... to what degree that goes, I actually met a guy, a teacher in Toronto, and it turned out to be like a little bit of a hook up thing in a way we had no sex-sex, you know, he came, I didn't even come he didn't give me oral. I mean we kissed, you know, we made out and you know he had an orgasm but that was it. He wanted to come visit me, I shared with him at that point my HIV status at which point he freaked out. The thing that makes that interesting is he did hiv counseling and education in Toronto. So he was teaching you know high school and teenage people about hiv awareness. And here's a guy who's a counselor who's supposed to be knowledgeable about it, freaked out when I told him the fact that he went to get tested, he had to wait 2 weeks for his test and he was all up in arms and he was telling his friends and asked me how could I do that, how could I not disclose, and this is someone who I kissed, had no orgasm, I had no... there was absolutely zero chance, zero zero zero that he was getting anything from me. And uh I was on meds at the time too and was undetectable so I know that there was zero zero. And that's the reaction of someone who supposedly... and..and..yeah was teaching kids. And I kinda got upset with him at a point, you know it's like well what's going to happen if some 19 year old kid comes to tell you they're positive are you going to be able to put your arms around them, give them a hug, tell them it's going to be okay? Are you going to be able to kiss them is that okay or are you going to like push them away? But that's... and he said well I don't care what...you know the doctor's say, I don't care what the...you know the...the percentages are and all this is me, you put me at risk. It's like, no I didn't put you at risk. So and you're aware of it. That kind of shows you just the perception of him from someone who is quote an HIV educator, to the young people and his feelings. Just think about the people who don't know. And most people don't know, they don't want to know, they fear it so they just...anything associated with it it's kind of like you want to run, which is why I do believe a lot of people aren't getting tested because they don't want to know. They're hoping. And and when you tell someone oh yeah I'm negative in their minds it's like oh everything is okay now. So people realign and say if someone says their negative it's like oh okay well then they're negative I'm negative too let's go.

Opt-out work increasing testing?

I don't know. I don't quite understand the opting out. I think it should be mandatory. I think most people would want to know. I think the people who don't want to know are the people...would be the people in the high risk category for getting it. So, they actually probably should think, you know...I, from where I'm sitting now, of course people would say it goes against your civil rights and all, but they should probably make a law where you get... it's got to become a mandatory test. You want to end it? Make it a mandatory test. Like you said if everyone who had it they stuck them on meds right now it would wipe out the epidemic.

Mandatory reduce stigma?

Well, it would be interesting to see if they made it mandatory because you would get resistance, you'd get a lot of resistance. And it probably would never... it's a long way off if it gets to that point. Um, right now if you did it you would get the resistance. I don't think it would take off the stigma. It would be a wkwaee up call to a lot of people um because it really... you know it kind of hits them square where they are. In my opinion though from what you're saying the stigma reduce the stigma, there needs to be...um.. instead of... people are talking from the prevention of what's wrong. There needs to be more education on the HIV itself and being on meds and people who are positive and how you can interact with them. They should tell people it's like, now see doctors don't want to do this and they won't say this but it's kind of like if you're in a hook up situation, because we're talking from a sexual silence is where we're coming from but in a hook up situation and I was talking to him and some doctors have a couple different opinions and some doctors in the know won't confirm some of it because we don't know if we want to do that it promotes it, but in a hook up situation you either go to the doctor's and you get tested together see if you're negative, which never happens, people just do it, or you know one of the safest things is someone who's truly negative is your safest. The second safest is someone who's actually positive who know's their status who's on meds who's undetectable and you play safe. It's one of the safest people you can be with. Because someone who thinks their negative if they're not, they are... if they've recently seroconverted, they could just be teeming with all these super high viral loads. Which is what happens, which is why we see clusters of people being infected. But until the community understands that...until the...the... positive... being HIV positive is accepted in the community, is not looked on as leprosy and a pariah and becoming a stigma you're going to have people being afraid to test. If they make mandatory testing, they had to get tested, I think some of the people who have those attitudes will start to shift because people closer to them and the number including themselves who had that opinion and were like that will all of a sudden wind up in the same boat and when the shoe all of a sudden comes your way... it's....you know...it's a new day. I don't know that I was... I was never like a pliant, I've always been on the outside needless now I'm getting more in there were guys who I knew were positive and were open about it and I chose to not have sex with them. It's kind of like well I can be your friend but I can't you know, have sex with you. I wasn't knowledgeable. After I became positive I found out, looking on some sites, I found a couple people who I had been out with and gone on dates with and found out they were positive who never shared it but I was never in a situation where I was at risk either. But... so I...I know a lot more why people do what they do now.

Opt-out reduce stigma by treating it like any other normally screened disease.

Definitely. It definitely is going to help. And when you bring that into the mainstream people understand as more people are affected, people understand as more like women because it's always been talked oh it's a gay disease which I mean it's more... you know the possibly not a gay disease a number of women that have it and it's changing. I'm sure it's changing. And I think that...see the majority of Americans in the mainstream probably wouldn't even know that ...that..that it's on the grow with women, which tells me . does tell me that there's a lot of men on the quote down low that are bringing it back. And there yeah should be mandatory testing, and it should be tested with everything. And... especially in the with the women they should...I think they would be appreciative because guys tend to roam by their nature and uh...the doctor should be able to uh.. to test for that. I think it would help. It would have to help reduce in time. The bigger thing in that is that if everyone is getting tested is that they know and from a health standpoint for themselves and for others... it will, it should, it would curb the epidemic. If everyone got tested that

had to, and everyone knew, it would... some things would change... quickly. And if you put them on meds you would knock it out.

Taking away pretest counseling requirements? Oral consent enough? Opinion?

I can't remember all that I went through when I went in there. I know you had to fill out a thing and all, and you get tested. Um, anything that makes it easier and more accessible is going to be helpful. Um, it's not... people aren't going because... people are not going to get tested because oh yeah I did that once and I had to fill out all that paperwork and do it, that's not why they're going... why they're not going. Because that takes 10 minutes, so the whole thing it might be a half hour of your time to go and get tested. They're not getting tested because they don't want to know.

So you're saying paperwork is not a barrier.

I...for me the time I went it's not a barrier. I cannot think that that's the main issue of why people aren't getting tested. I do think that...that...uh, part of it is people...there needs to be more awareness where you can get tested. I think there's a lack of information on where you can get tested, and when. Uh you know that's like at the bars and stuff they have...what do they give out... they give out condoms, and all...like...on HIV prevention. But where does it say...I don't see stuff. I don't go out that much but I don't see things it's like oh here's where you can get tested. I don't see things on...every once in a while you'll see something like a manhunt if there's an HIV thing or you might see something on a craigslist but there's nothing...it's not like...in your...it's not in your face. There's not that much awareness about it. I think there needs to be more on you know...there needs to be more education, more understanding what it is understanding people. And I think telling people who are on meds, who are undetectable, they need to understand what does undetectable mean? What is healthy positive? That's what I wrote in health of us is how can somebody be healthy and positive? I said that's an oxymoron. That's like someone with terminal cancer you're saying they're healthy. And I answered their question, it was in a Minneapolis thing and I had five people write to me, thank me for writing it and education and some people, one guy told me said hey I've been positive with my boyfriend, my ex-boyfriend, and we were together I'm a positive sexy male or whatever I was with my boyfriend for three years and we had...they had bareback sex, they consented because he was undetectable and on meds, and his partner is still negative. Which, in studies you see they do it in Africa, in the studies with husband and wives one's positive, one's negative but they're on meds, they're not...they're having kids, and it's being okay. I mean they can't like I know Palermo can't say...oh well, you know there's still a presence so you could get it. It's like well yeah there is a presence and you could, but there's been no known study...I think one in a thousand or less who's gotten it. So if you're undetectable, you're in good shape but most people don't understand it.

What about incentivized testing?

For people who do drugs that's a good thing. [laughs] it's like yeah baby give me some. Um, I don't...I don't think it would hurt. I think you could go ahead and you could...you could try it. Uh...you know...ultimately the best thing is to get some because the people who will...I...and this is what I wanted to asked the doctor I was kind of curious when he came here....it's like the people who are getting tested, my thought is probably most of the people who are getting tested are the people that are playing safe. There's....you know...The problem is where the people who are having unprotected sex. And some of those people are definitely getting tested, but I still think that in large majority they're not, or they're not getting it done consistently enough, and that's the...that's where the heart of hearts is. And I still think that with some of those people, it's still going to...it could be...I mean I don't know this for sure, but it's just my thought so I can be tough.... to reach because the

reason we're growing is because they're not getting tested, it's not the paperwork. I think that people need to have more awareness of where you go, because that was my first thing, I had to call a friend and say where do you go to get... where do you get tested in Philadelphia? I don't know. I didn't even know where you go to get tested in Chicago except for my one clinic they did it, so...

Would there be a specific dollar amount tipping point to get people to get tested?

Make it 5, 10 bucks I don't know, something for 10 bucks for a half hour they're going to come do it. For 10 bucks I might go get tested [laughs], you know? I mean if you give it, if someone is negative and they knew they're negative and they could go, you could go...you could go... I think, that's not a bad idea though, or to have movie tickets especially if you are promoting locations. They need to promote the locations and the times. And people have to know...that it's...probably because the people that work there are going to know, someone's going to know so even then, you know, people get known there. You know their status, which is kinda...you know...that's why I know with sometimes you have, it's when they have anonymous so you can make the choice because there's something, if you wanted something, there used to be the rapid test and if you wanted it you had to let them know your name or whatever, and if you were positive then they had to turn it over to the state and all...so then there's that big fear factor. Uh, if there was a way that testing could be done and like they had a number and they found out after or even sent the information, that might...that might get more people, that might not let people know. I know some people in Chicago from talking to a doctor out there, there was some...one guy in particular actually tested positive, but swore...he still swore he was negative and was still having unprotected sex. Of course he was infecting everyone around him. And uh, it's like what do you do at that point? But in his mind he was convinced he that he was not positive even though he tested positive. And uh... the real key is getting people in, and I think one of...further you said, opting out, making it part of...I think that's helpful, making it part of...uh normal testing for everything else. Uh, I also think making people more aware of where the locations are and the times that they're available is huge. That's what I was telling him, I was going to put on...what drug disease free, that's what everyone puts drug disease free for UB2 and I was going to put a little thing in there, ask them where they got tested. Because most people...they don't, they just don't know. I don't even know where I got tested, or where I thought I got tested. I don't even...think the place is there anymore. I think they moved. William way is probably where...they probably do testing there but I think it was somewhere else. But uh, that would definitely be helpful. I think if you were doing a campaign to have a test and doing that, you would get...you probably could get some more people to come in if you're doing the dollars. Uh, the challenge still is the people coming in, it's like well what if they test positive? Do the people there know? Do they want their friend... all of a sudden it's kind of like they know and then people...I remember the one time I was in there the guys that were getting tested, they were like freaking out...just doing the test. They were freaking out because it's....what it does is it brings reality...it's...it's...reality. And the reality that hey, you know, you're actually getting tested to see if you really have this. So, there's just a...there's a number...I just think there's a large majority that don't want to know. And I think they don't want to know because of the stigma. Reduce the stigma, make it more...and I think like you said the opting out is part of it, uh make people more aware that it's not leprosy, and when treated, and treated correctly, the more thing is telling positive people hey are you on meds, and you know, are you undetectable, so you know.

Elaborate more on mandatory, implications of making it mandatory.

Uh, the implications of mandatory are the...I think yeah, it would be great for mandatory and you'd have to have a record of it like when you renewed your driver's license, having an HIV test. Well of course, some people don't have it..a driver's license. But you know, with...with certain things and I

think...because I think when it's mandatory then they're going to know. Because the people that are at the risk, that are passing on. The majority of people passing it on don't know they have it. And they're not testing to see, they're not taking these precautions. And they're not...they're not testing because it would change....it would change their lifestyle, it would change what they do. I'm talking more from the...the...just from the sex thing. It would change what they do.

Change from all aspects of their life?

It would change in the fact that, hopefully they had enough of a conscience that, you know, it's...the reality is it's kind of like dude you're not negative anymore you're positive. So, they might not tell anyone. It would just, it would just change their assay because all of a sudden now that you are you have to deal with the reality that everyone goes through that you feel that...oh am I going to die, is my face going to like...shrink, am I going to be atrophied all the different things that were associated with in the early years, which it's still...you know a concern and it's like, you know am I going to live because it's still thought of as a death sentence by many and... a plague.

How change idea that it's a death sentence?

See they did a campaign once about positive people from what I was told, and how they were doing all these things, and also then it almost worked to a counterpoint that people were saying oh, well if I get it, I get it. It's no big deal, you take a few...pop a few pills and you know, you're back up to speed and then you can just kind of roll along. And some people definitely have that attitude. So they have to understand that it is serious, but that it is manageable. I do know the cdc moved diabetes ahead of HIV for cause of death.

I'm not positive.. I'm not 100% sure, but.

You're not positive, you're not positive but I'm positive. Literally and figuratively [laughs] on that one that they moved it ahead. And it's actually that...uh...I think it was that uh, HIV actually was more manageable than diabetes. And when you know follow proper regimen and do all that so, uh yeah. But that's... the testing thing I think you can throw out the things with the money, I'm not...I'm still not sure if that's the big thing. I think they need to make people aware of where they can get tested and the locations. And that has to be more visible. In my mind visible in the gay community is the bars. I mean that's the big thing, and it's not visible. You really have to work to find your spot and when it's open.

Tell me more about mandatory and the idea of civil liberties. How do you feel about it and does it interfere with right to chose?

It...you know what that's where the civil liberties and they just push the envelope. It's bullshit. It's like you know what let them do that but then also you know, make them responsible. If it comes back they find out that they do have and they've infected people let them pay for the care, which they can. Which, which most people can. And I think...the civil liberty thing, everything is just so...taken out of proportion. I mean the civil liberties, it's like basically...it's like if you're not... see if you're not going to do what you need to for yourself, like get tested, then you should...it should be mandatory to get tested to make sure that one you're okay for your own self but as a protection to the other people around, and that's the thing. The big thing that's going to make it hard, why it would never be...and the mandatory would be hard because of the...in the mainstream society, from the work standpoint and stuff. I mean people lose jobs, and not only being disowned from the one thing, it changes things as people are just...they fear it, because the mainstream even more so. I've been giving you answers more like from the gay standpoint, and the gay community. But in the mainstream it's even more of a stigma. I mean way more of a stigma. So we're even more guarded about it. So...That didn't answer your question did it?

It does, a little bit. So from my understanding of what you said, it's kind of like sacrificing individual rights for the greater good of everyone else, and that balances out...

In a sense but what's an individual...I guess it's someone's individual right if they want to you know let a disease ravage their bodies. Um, as long as they want to pay for it. But I think an individual right, if it's something...just in a sense people should take that precaution. It's a government...you know you look at the cost and the health cost and the burden that's going to be put on all of us. You know, there's...there's I don't know. One thing is I'm not, I'm into less government but in something like that, the opting out is a very good...the opting out. Doing it as a standard test I think is a very good thing, and for people to do their annual physical...it should just be...it should be mandatory. And anyone who wants to opt out of it, that's to me it's a major red flag. There's no...would you think...because I think no one...who would want...it's like okay I'll take it, what's the big deal, no biggie.

Opting out indicates that there's something that needs to be followed up on?

Oh yeah. But do you think so?

Possibly?

So now you're maybe thinking oh no just because he has individual rights. But it's like no rights, but I'm thinking if someone...why wouldn't someone want to take a test and you think if you're not at risk or you don't have it, it's like yeah go ahead. But they're saying oh I could never have HIV, no I don't want that. The only person who would opt out is like if someone has a secret life going on, something going on, or they know in their world that while they think they are, mentally they've convinced themselves they are because they've never been tested and they feel alright. But they don't know for sure, and they've exposed themselves in an area where it's possible they could have it but they don't want anyone else to know. And they don't know, and in their defense they would say the only people who would opt out of that, like they really have to believe are...well the goofs who talk about their civil rights and they shouldn't be tested for that. And for people that could, you know, have exposed themselves in a way in some manner, I mean it could be through drugs or whatever, too through needles or whatever that they could...they could potentially have it through some of their actions.

I know you had mentioned making it mandatory through driver's license. Any other example of mandatory? Example of pregnant women in Connecticut, federal prisons.

Annual physical. Your annual physical. And you could do it for the dentist, but that wouldn't go over well.

What do you mean?

The dentist?

Oh right.

So it's like they prepare and all, and it's supposed to be prepared against but everyone does, but it's like where do people go? Because not a lot of people get physicals. I mean you go to your doctor, and you have the younger people. I mean the other thing...I was going to say sometimes you do testing in bars. Most people aren't going to get the test. If you make it mandatory to go out to the bar. [laughs] You got to get a card, I mean that's another thing with mandatory. I guess you could have a...I don't know if you can carry a card, that's...yeah...it's too much a private or a personal thing. I'm trying to think of mandatory, other mandatory things. It's just something that normally

comes up. An annual physical would be...getting any blood-work done. But you need that, it's just a little prod that could just be a regular, a mandatory routine type....a routine checkup.

So mandating that all physicians do annual checkups that include an HIV test?

I don't think there's a bad idea...now you do the opt-out. I think if you want to do the opt-out, they can do the opt-out. But that would be...that's probably. It just picks up another segment, a big segment of the population. I mean that's uh, you could make a recommendation. But I think that would be uh, you know the thing. But I actually have my thing they were supposed to...I got my records from a year and a half. And, this kind of goes like in the straight world because it pretty much was...you know, living in the straight world I've been married, but they were supposed to test for HIV. They were supposed to test for viruses. I thought they had, but they hadn't done the test. So they just thought, oh...you just have parasites. But as it turned out, by not doing that test, that really...it put me behind the 8 ball a little bit. I don't know if I would have been ready at the time, but it just goes to show that a lot of times in the community you just assume, oh, that can't affect us and that can't be in this world, and I think that's just a precaution, they should do it because you really don't know. Like, I would be the last one people would suspect who would have had it.

Out of all the different types of testing, is there one that comes to mind that would be most effective in getting people to test.

Type of testing? Well I know they did the oral...the little swab, but then they said that wasn't very reliable because they were getting false positives. And I don't think, you don't need false positives because you could put...it could be a traumatic, it's a traumatic experience in no case. I mean it's probably still the easiest. Uh, and you know...then of course if you have that done then they say you need to go get a blood test done just to confirm one way or the other. But the little, I think just the little finger prick. I mean they say that blood is the most accurate.

What about opt-out, versus incentivized, versus mandatory?

Well if you're making it mandatory, if it's mandatory it's like mandatory is mandatory. So um, mandatory is going to be the one. And you're still going to miss people. Because people aren't...because however you do that, if you're doing physicals, you're going to have people that miss physicals. If you make it mandatory and they got a, and they actually got a card. You know like in the gay community, and this could be opposable, but you get like a....you're getting...see but that comes to disclosure if you get an HIV card. But for a lot of people you know if you're having sex you could know, at least you would know a little better... of course it's only as good as your last test. People get tested that are negative and then they go around messing with 10 guys. Your test is only as good as your last hook up. [pauses] It's like a whole new world isn't it? [laughs] Gay 101! [laughs] It's like what are those men doing out there? Oh my god! [laughs] it's like oh! We need to stick them on an island and they can do whatever!

Any additional questions/comments/ideas that come to mind?

I don't think so. The questions... it really is about you know, it's about education. At least I know in the gay community it's educating to what HIV... a lot of people don't understand it. They just know it's a disease, I don't want it, I don't want to know about it. And they're kind of like this, I don't want to look. And you know they're doing the things they don't want to know it's like, oh. And I asked my friend the other day said why you know do people like at zero hour like they'll ask...you know like if they hook up with someone at the bar and they go home then they wait and they get all their clothes off it's like oh, you're drug disease free right? You're negative right? And they say it, and it's like in that situation what are you going to say to that person? Well maybe they just have to say it

for their conscience. Because of what they're doing, and it makes them feel better. And you know, you say that and uh. But people need to treat, in dating, they need to treat...they need to behave as if everyone were positive. And most people don't do that. They...as soon as someone thinks someone is negative, or is not talked about, they let their guard down. Because in their mind they rationalize it away. But you see if someone is positive, and they put it out there, hey I'm positive, in a sense it's like oh positive can I get it, no stay away. And what most people don't understand is that a positive person who's being against positive people are more, we don't want, if you pick up one of those STDs that are out there it hurts your numbers. For the positive people that are aware and care about that stuff, it's kind of important. So that they want to...you know they're going to have sex with someone, want to have someone who's understanding that's a little more, because it's as much of I don't want to give anything to anybody I don't want to get anything from anybody. So, and but that isn't being communicated or understood at all. So it's, it's taking it from that other end. The prevention end...people are going to do what they're going to do. It's what's going to happen. That's just really what's happening. And people, and my thing is, people who are bare backing it's like you better go get tested ahead of time or you better be with somebody who's positive, who's undetectable and on meds. And let them show you their meds because people can say oh yeah I'm on meds, I'm undetectable. And they could have it, it's like yeah show me your meds and I'll see you're taking them. And know your counts. And that's the only way...the more that people understand that it's okay... magic Johnson did a fair amount. I mean, I mean He's doing some things on some levels. Of course some people now think, there's a rumor out there that he lied that he didn't really have it, used it as a propaganda, which yeah right, he ended...he stopped playing basketball because he lied because he had HIV. So that's, I think the gist of what I would say. Hopefully I was helpful.

Demographics:

48, white, private insurance, above \$100,000, college, employed.

Subject #007

When were you first tested?

Uh well I was first tested in prison. I was in prison in the county jail. And when they called me back, after the testing and let me know what my status was, I wasn't sure I wanted to get more...wanted to...you know because it hit me all at one time. A lot of it being incarcerated. I said well...I was trying to shake it off mentally. But then I said well when I get home I'm going to get some more testing done because you don't get the right treatment when you're in prison.

So it was required?

Well it wasn't required, but it was just my blood pressure was giving signs that I needed to have some kind of testing.

So they got your blood work, and they also tested you to HIV?

Yeah they got my blood work, and I agreed to the testing for the other stuff so.

How did they ask you about the testing?

Well actually, you noticing that they started...you see you know HIV testing in prison isn't popular like it is out here in the healthcare world. I was having problems with my blood pressure. I was actually just catching colds, maybe had some abscesses on my tooth, and the signs, you know, of HIV...maybe. so they did the blood work and it showed me that I had full-blown AIDS. That's what she came back and told me. And you know...I don't think that she was doing...she gave me the information in a professional manner because of her output of clients in the prison. So I said maybe when I get home I'll get more testing done.

When was this done?

This was in 2005...2004 or 2005.

That was the very first time you got tested?

Yeah.

How did you feel when you got your results back?

Well, opposed to going directly to a depression mode and debating whether I wanted to get into medication in the prisons when my body was just lying dormant and I wouldn't have...wouldn't be able to have the activities to burn that medication, to work that medication. So I...I...uh, I mean I felt crazy. I felt...I just put myself into my regular prison program because you know it would tear you apart laying there at night thinking about what's going on in your body after what somebody told you and then they're not giving you all the education about it.

So you kept yourself active?

Yeah, I just kept myself busy with the prison program opposed to what the medical folks were coming after me with, you following me? And that's how I maintain, and I haven't been back to jail since.

How long did it take you to come to grips with your diagnosis?

Alright, when I came home... I came home on the forensics treatment program, a drug and alcohol program. And the counselors in Gaudenzia actually was doing some HIV testing they was referring me to...actually they referred me to the Partnership. Gaudenzia referred me to the Partnership. And

uh...And then the staff here is who helped...gave me some education about what was going on with my blood and stuff so. You know other than that I didn't know much, I didn't go to school to be no blood doctors and all that stuff. So I sorta listened to them and they were explaining it to me in a professional manner so I started taking treatment.

Was it pretty soon after you got your diagnosis that you got treatment?

Oh yeah from partnership yes it was. I was a little defiant at first about taking medication because they started me on atripla. And you know any medication that you take your body has to become accustomed to it so. My bowels and stuff were going through changes and you know, it was crazy. So then Dr. Lee he came, he became my doctor because the first doctor I had here I wasn't taking that medicine. And then Dr. Lee came, which is a male doctor, he explained things to me a little more, in a way that I understood and then I started taking medication. And I figured he wasn't trying to hurt me, he was trying to help me and today is proof of it. My counts are better.

Changes in testing recommendations. VCT to opt-out, pretest requirements as barrier to testing, removal of pretest counseling and written consent requirements.

Opt-out testing...I mean like as long as a person understand which way the testing is taking him towards, I mean I don't see...plus you have to have the client or patient understanding where he's at with his health. Once he understands that and he's comfortable understanding where you can help him at, and where you see there is a need at...I think it's a good thing. I think opt out is really...can really help you with some things.

Do you think it is beneficial to do testing in this manner?

Well yeah if they don't feel comfortable, yeah. Maybe they just haven't...not there yet...not comfortable with that yet. Maybe they need to understand better about it. So maybe it need to be explained in detail...a little more in detail. People understand on different levels, different thinking patterns. And a lot of people are secure about their information. Cause a lot of times, I'm in the clinic, like if I come to this clinic everybody know what this clinic is about, what this clinic do. So you know. A lot of people don't feel like being...just having that much more discretion for themselves until they come out of the closet about where they at with themselves and their own personal health, they ain't going to be comfortable.

Will it get more people to test?

Well, I'm at the point where each on teach one. So I would bring somebody here that was comfortable with opt-out. I think people will...once they come to light with where they at and where they want to be, I think opt-out will be comfortable.

Removes stigma surrounding disease. Do you think opt-out will remove fear associated with HIV testing?

Mmm, possibly. Because, I don't really...it depends on where the person at. And then you look at your society in general and you figure you know, the reforms...and the cost of living, and you know the people in their state of mind and the economy you know. I don't know. Sometimes people they be thinking about material things before their health. So you need opt-out there to keep people informed about their health needs and things like that. And once you have a community together that that's knows that opt-out is going to give them the first class information about their health status and everything, I don't see why not. I don't think it'd be a problem .but you have to understand why everyone isn't coming opt-out because there are economic forces out there that's in the way of people worrying about their health on a third scale...you know. Instead of third class

mail instead of first class. That's supposed to be priority your health care, but a lot of people can't afford to take time out to come see about their health because they're forced with all those other social economic problems, financial statuses and trying to keep up with that, all that. Because you know...i know a lot of people out there right now that probably could be, because sometimes once you understand the hiv virus and everything you could just about talk to a person and put his whole character in check and tell whether that they need to go get their health a little bit more, you know. It becomes apparent after a while. But I think the education portion is important that we understand where we at with our health.

So why is education important?

Because the less you know about...education is about knowing, you know. Knowing where you're at with a particular topic, and then the more of a community you have that don't know about, you know. Then you just wait till one fall and one at a time they just keep falling until there is a rude awakening, you never know how you missed out, what you missed out on. Yeah you're missing out on a lot of things. Like I'm 25 years behind and you know...I grew up on the streets, so I'm just about learning now that my health should have been important years ago and my little habits, and the way I did things and where I did things at should have been conscious. But when you come up in a community or an environment where there's no education, you know...

Education about health or in general?

Education in general because had I known about HIV when I was in junior high school, I probably wouldn't be on the meds and stuff I'm on today because I would have had...my behaviors wouldn't have brung me to that point, you following me? So yeah, that's what's important the education part. Getting it out into the community early, early in age. Right. Then you won't have a generation higher than the other. You following me, yeah? That's just about where I'm thinking about. And I think opt-out is doing a good thing, trying to grab the community. But they got a flood of the upper community, and they need to feed more information to the lower community before they get up there, and then maybe you can bring this epidemic down some. That's just my way of thinking.

Incentivized testing as way to get people to test.

Incentivized? I've never heard of that.

Giving gifts to people, like movie tickets.

That's good, but you see the people that really need to be tested are teenagers. Teenagers and stuff like that because a lotta them kids is running around with...with the venereal diseases and stuff and they letting it sit all in their body because they're not around the people who keep them educated about how they should be looking out for theyself. Because you know...I remember when I was a kid I used to get burnt, I used to be running burning dripping and stuff, and I wouldn't go to the center until I got real...couldn't even piss you know. So, you know, but I didn't have...I wasn't...in the community where I could go explain that to somebody, you know, where to go. And then I learned about the district health centers. I used to go get shots like that. But like I said the education wasn't in the community. That's where I go back to where I said we're not properly informed out there about you know what's going on with ourselves and this world. So I had to learn when I got older.

Specific type of incentive that will get the most number of people to test?

Something that the customers are seeing everyday. Something where like you know...I know that when I get up and come outside, I have to do...I do certain things and I'm with certain people every day. Like now I'm in the community where I'm getting HIV education and I'm dealing with everybody

has HIV and treatments. Mental health treatments and stuff like that. And with project teach, that's all we do. We learn about the CD4 counts, we learn about the viral loads and all that. And advocate, self-advocate. You don't learn to self-advocate until you get older. A child ain't gonna know how to self-advocate for itself. So, the information's got to be out there for them to see. It's like in the closet. I'm not going around advertising yeah I got HIV this and that, but I'm going to see the little healthy things I did and I didn't do. And the little things that I might see a youngun doing now, that might not be to his advantage, I might say something like that. You know, that's self-advocating. I don't know. I see it as being a good thing, but you need to do more. The programs need to do more. They need to filter information out into communities throughout. We can sit back and do all the research we want but until we get to the community to change the little social habits that's going on that's causing all this, we're not going to be able to put an impact on you know. On this thing. Just keep on doing research keep on doing research. And then we gonna be keep on trying to catch up to something that's getting ahead of us, you following me, instead of coming back down to a level...to a level playing field and spreading out that love and that information and letting people know before they get up there where we at. That's what we got to do, we got to come back down to the level and let people know don't be doing those things and don't be getting into all these activities that got us where we at, taking all these medications and stuff. That's where I'm at today.

Giving people money versus tickets most motivating?

No, I think giving people a movie ticket to see what's going on with themselves. But the influence of the movie is important. I wouldn't give nobody no ticket to go to the movies to see somebody shooting up police officers and stuff. But that's the problem we got in the world today. I'll give somebody a ticket to go to a movie to see how to take care of they health, how the little...how important it is to keep the insides of their fingernails clean and brush they teeth and stuff like that. The little things I didn't do when I came up in the streets. Now that I can see the other side, it's important to take it out of there.

Good to give people gifts to come in to take a test?

I think it's an attraction to get your information across. Now if I was to give...if I was to give an event that offered games, a smorgasbord, stuff to the communities to teach, to pass on information about a health risk or something like that. I think it's a good thing. As long as the information is informed.

How to create link between inform people and get them to test?

I guess it would probably start in the community. It would depend on what you testing for. Like in my situation if you're testing for HIV, you have to um, inform the community about where the HIV is most likely to come from, and where all your clients and patients are most likely to come from. You have to look at like I said the economic forces. Some have and some have not you know to live properly. I think you can start there. You can filter all your research there and get your information and try to help them.

So start from community.

Yeah, communities. Community based projects are what's going on now. That's basically where the HIV is breeding. Even in the mainline, the casinos, hotels and stuff like that. Information is just not popular like it used to be. I know when the cigarettes started, they...billboards everywhere [laughs]. Billboards everywhere.

So just by making information more widely available.

Yeah making information more available. I think that you know, lotta people will step up and see where they're at.

Why is that?

See now because I guess in the working class people, you'd be surprised at people walking around with HIV and they don't even know it yet until something hit them. And then now you got to request to have an HIV screening. Because it's not really required. Until people start getting sick, that's when they start getting treatment.

How get people to test before they get sick?

The education part. You have to solicit the information. Worksites...you have to solicit in places early. Early, like...solicit to me yeah I'm ready I need it I know I need it. But you gotta get it at the core first.

How early?

I guess you could start soliciting in junior high school. I would start there if I was an economic force with the power to facilitate that information. I would start in junior high schools. High schools. I would start there. In the health education department. I'm quite sure they have a phys ed department. I don't know what they're doing in schools now. I don't know what they teaching them younguns now. But it would be, you would think that the education needs to start early. 20 years from now, we'll see different numbers. Maybe 10-15 years we'd see different numbers and we start early education of HIV. I'm a strong supporter of that.

Mandatory testing. Have to test. example of pregnant women in Connecticut.

That's a her piece though. If it's mandatory in Connecticut that women pregnant and...I mean...does it have to be some physical signs? Does the woman have to display physical signs?

No, just when they go for checkups, get tested.

So they have to do HIV test?

Yeah, even if they never get checkups, when they go into labor the doctor will test.

Oh yeah? I don't know how I'd feel about that because its opening up some other Pandora's box. Because if she wasn't showing any HIV symptoms, you following me, so where would I come at my patient? I would look for everything else. But why would I mention that? I guess the only reason why they'd do that...but.

Why only test when have symptoms?

I guess it'd be good to see how strong their immune system is, that's about it. I guess that's about the only information that they really can get out of it opposed to putting them into some type of depression you now? Like I said, depending on the way you live and your comfort zone, it can really be depressing knowing your status. Knowing what you passing on. Then you got to explain to the father, she got to explain to the father. Then he might have to go get tested. Then what impact it might have on the child. I think sometimes, as far as being mandatory. I think you should just let it wait itself out, wait for the symptoms, wait for earlier symptoms, or wait till you have the baby and then have them both tested. That would be the research part. If you wanted to come back and do that. I mean as long as everything is health and you ain't showing no signs.

The hope is that if test people early, can prevent them from having a lot of damage to their immune system. By the time they show signs, may already have progressed to AIDS.

Well see that...that...no testings, I guess they gonna update....but testing can throw you off too. Testing has they ups and down too. And everybody's blood is different, type is different. I forgot...how they did that. But, I don't know. I would...I mean, I would ask them first if they want it. But as for it being mandatory...don't know. Don't tell me about it. Let me go through....let me have this child first and then tell me about it and then we manage it [laughs] you following me? Ah yeah take the test but keep it to yourself. Keep it on record. And then after I have the child, then I can get through this mentally stable. Have my mental stability. I mean, it's scary though to some people.

Mandatory work getting people to test?

I think people will...I think...like I said a lotta people don't have the education about it. First if you gonna give someone HIV testing, you gotta explain to them what it consists of and how it gonna help.

I think you draw more resistance.

Why is that?

Why should i... why...when you say mandatory it's a requirement. So... I don't know. It's hard to tell. You could tell the young folks that, young kids having babies, having babies. No, I don't want to be tested. Tested for what? Ain't nothing wrong with me. A lot of it is about attitude too. You know, hwen you say mandatory you discourage them a little more. They don't want to do nothing, they just go somewhere else. You say mandatory, as opposed to giving lots of information. And then you compare the two sides. You want to test me, I'll see where I'm at. I might be with my...she might be with her girlfriend or something. And she don't want to know what she might be going up against. Because people get funny when you... oh you got HIV, you coming to this clinic, I ain't messing with you no more. Yuou know what I mean? People get funny like that, but you gotta know what you want. Like I said alotta people aren't educated about this. People don't know what HIV means, or what counts means. And its important that we get that information. But um, right now it's like a secret world, a secret society.

Other than education, what can we do to get people to get tested?

I guess, we gotta facilitate the information out to them. Start it early. Had I known some of the things that I know today about the HIV virus and how you can acquire it, I would have had some healthier habits. I believe that. Junior high kids don't know what a district health center is. Costs, and the effect .and they don't know how to go about taking action.

Out of the three types testing, which will work best to get the most people to test?

The opt-out, the first one.

Why you feel that way?

The opt-out opens doors. The door is open. The information is there. Opt-out is like you ready when you want the information. They have it for you. So you know, I more like that.

Additional comments? Questions?

I always stress that, I still think that the health department has to do more to get the information out to these communities, you know...these urban communities. They need the information you know. The information is vital. By this...by this..generation changing over to the computer world,

everything on the computer, it's not like...it's not like, things have changed. Ain't nothing like it used to be. Cause you know people are online all day, people aren't coming out they on the computer, they aren't coming out to get that information. If you can get that information out on the internet to inform people to get tested, to keep their counts. I haven't run across a site like that yet. That's something to think about. if I had some power, I'd put up a site like that. Educate people how, what they, what they count is, what HIV is, what age is, the progressing stages and all that stuff. I'd probably do something like that.

What if people were fully educated, but still weren't getting tested? What to do then? How to get tested?

Gotta get out the office and advocate, let people know that. I don't know.

If everyone knew everything, but still not testing, what do we do then?

Well...I really, I mean it's a personal decision about your health. And a lot of people are in their closet about their health. What do we do to get them out of the closet, that's basically what you asking. What do we do to get them out of the closet. Like I said, I go back to my famous model each one gotta teach one. If I knew somebody who I see was ailing and may have the virus or something, or was sick. I wouldn't even...some people are offended if you say you sick or all that. I would advise them to seek medical help or advice, because I think you can do better than what you is, and I can see your health is ailing. You know, so. All you can do is advocate for self and for others to seek medical attention. What can we do to keep them coming out of the closet? Put it out there on the tv, everywhere. Mind is coming out...you know channel 35. Yeah. Well we need programs like that on HIV and all that. And they do. Once in a while I'll see a program on mind that talks about HIV status.

What about people who don't look like they're sick? What can we do to get them to test?

Like I said, the advertisement, the awareness. The literature. A lot more literature. Like they give out the free METRO. You know how many millions of metros go out in the city? There should be some sections in there. Learn more about your HIV status. And this, just learn what a CD4 counts are, viral loads and all that. And people will start paying attention to their health and wanting to look up and keep up. I've been on meds for 3-4 years now, and I've been feeling better and better every day about myself every because I know I'm working on myself.

Just to summarize, you prefer opt-out, but feel mandatory isn't too fair...

Right, mandatory isn't fair. Because it can play emotional, it can play an emotional part on a person. Especially ladies won't seek treatment because I'm gonna feel you...putting me under the microscope or something. Some people will feel offended. Until you just about to get bold about yourself, and say I want to do me, I want to take care of me, I want to get me back in shape. Until you develop that attitude, you gonna be in the closet. I don't like mandatory. What was the other one?

Incentivized.

Nah, I ain't like that one either. I like opt-out.

Demographics

49, African American, GED, less than \$20,000, public insurance, unemployed.

Subject #008

Introductory statements, can skip question if don't feel comfortable answering. Circumstances regarding when first tested.

Um when I first got tested um I was kind of nervous because I knew that I may have the disease and I was kind of scared so what helped me go through with it was one of my ex partners and he was telling me you really need to do it because it's for you and um or I had to give me things to go through this, it was like I just needed like the pep talk to get through it. Other than that when I found out the results I was kind of... well I was in shock because I knew I had it you know, and once I got the results it was kind of more shocking and I got depressed and things like that and I didn't think I was going to live, I didn't think there was anything to live for so...um, with the help of my family telling me you know, everything to live for, you know... just take your meds eat right keep a lot of rest, and with the help of doctors here, it's been pretty good for me you know last time it's been a few years since I had it.

When was this first test?

It was in 2006, July that I had it.

Anonymous or confidential?

It was confidential

Any difficulty in getting tested?

Yeah, I did. Um, I was really depressed like I said before. And it was like I didn't want to go through with it because like ... it was like you know I have kids and I didn't want to have to tell them later on this is what daddy has, this is what I was facing with and you know it's like it's kind of hard because you have so many people saying um...umm.. people died after having it and things like that. So it's like kind of hard to live with and sometimes you kinda forget it and you don't want to forget that you do have it because you can get sick again, back to where you started. I started out pretty bad, my health was really bad, um I got really skinny, and things like that started happening. That's where I knew I had to live for me, do right.

Treatment immediately after?

Yeah, I immediately start uh treatment because um, I didn't want to die. That's one thing I don't want to do. So um when I went and got the treatment um, I see how many pills I have to take and I got scared again. And I kinda like backed away from the medicine and once again I had to more coaching to take it because it was a lot of pills and I'm not a pill taker so I was like I don't know if I can go through with this I'd rather just die now. Yeah, so. Um, you know, it's like having something to live for like the kids, mainly they help you. They help you a lot, it's why you're where, the purpose.

Pre/post test counseling?

No, I didn't receive any counseling, it was all about keeping a strong mind and keeping your goals things like that for living.

So right before you got tested, did they tell you about prevention?

They told me about things that I could have did to prevent it, and actually I didn't even know how I got it. Um, I really...I only had like a few partners in my life. It was like who did I get it from? And

they hadn't even knew. I don't think they knew. if I did know, then I would tell them so that they could go get tested.

Tell me a little bit about what motivated you to get that first test.

Uh what motivated me was um my health because I really was healthy before that so I'm thinking like you know I was so healthy, you know look at my health it's failing I need to go get this test because I don't want anything funny to happen to me.

Opt-out testing, changes in testing recommendations.

I think it's a good program to have. Because I remember they didn't have anything like that when I first got tested. You know it was basically either you want to get the test or you don't. If you don't want to get the test, well then you're wasting my time. So, that's how much I think it's important that they do that. But before I even knew about it, most doctors didn't even say we want to test you for HIV do you want to get tested, which I think they should start asking their patients more.

Why is that important?

Because some people they...they forget. They forget that HIV even exists. Some people forget...and not even that. Some people just have a...have a fear of saying that I want to get HIV tested because they're scared or they don't even know they have it. So I think they should ask, the doctors.

Taking away written informed consent?

I think that's a good idea too. Verbally saying that I want to do this it should be good enough. Because once people start seeing paperwork they get scared too. They feel as though, you know, I'm going to put my signature to something, people are going to start to doubt...who may see this so you get nervous so they back away from the test.

Removing pretest counseling

I think they should have that because a lot of people really need that push. They need to know that it's not going to be the end of the world. You know, some think it's the end of the world when they find out they HIV...they just go crazy. That their life is just a waste, but it's not even that. It's more important to take care of yourself once you find out.

Incentivized testing, giving someone \$5, tickets to a game, etc.

Um, I really don't think like giving me something, like I said before, like giving me money to find out like if I'm HIV positive. That should be the biggest gift in the world just going to find out if you are. And the greatest gift is finding out that you're not. So it's like why pay me to go take a test? It's for my health, it's for my benefit, you know. Um, but I can see someone giving me like, um, a little gift card or something like that to go eat, or something like that. That's...that's kinda helping me go through with it, you know. Especially if I know I have it already, you know what I'm saying. It's kind of easing the moment, you know. Um, I think people should try that. They should try it, you know. But as far as money, giving you stuff like that to find out about your health is kinda out.

Specific dollar amount that's too much or too little?

I would say, I would say 5 bucks, 5 10 bucks to go find out if you're you know HIV positive or something like that. And you know, not only give it to the person, give it to the person who comes with them because that's helping them get there, you know. And I think that's the thing, too. Or keychains, pens, stuff like that...people...little things people like that.

You said that it should be something that people should do on their own, can you elaborate on that?

I would say that the greatest gift for me was finding out that I did have it, because that helped me realize where I need to change in my life. Not knowing that I didn't have it is like not receiving the gift. You know, I'm kinda like being overlooked. So going to take that test was like the best thing because like I could spread it to so many other people and not even know, and that's like taking away from other... you know what I'm saying, families and stuff like that. And once you find out that you have it, like I said that's the biggest gift...that's the biggest gift. And the greatest gift of all is finding out that you don't have it. That way because you know you can go ahead and live your life without taking a pill every day. You know putting yourself to a new schedule so I think that's the best thing, that's the biggest gift.

It's something that people should want do on their own?

They should want to do on their own yeah.

Why is that?

Knowing that your health is going to be great, that's the best thing. And knowing that it's not, it's still good because that way you know that you have it and you know what you need to do and you know what you need to focus on. But if you just want to die, hey, you know what I'm saying, nobody is going to care about that. You have to care for yourself.

So self-advocacy, proactive about own health.

Yeah, and being you know just self-motivated about you doing it. Um, I see a lot of commercials you know. They need to air more commercials. That...that...that'll help people be like you know what, I'm going to go get that test because you know... and then...I heard that they got like that, it's a new test that came out...it's a 20 minute thing..

The oral swab?

Yeah like real fast. In and outta there. I think that's time consuming, because some people don't have a lotta time to deal with things like that, getting a shot, stuff like that. I think that's good to. And I think they should tell people more about you know, the swab and stuff like that, which is so much faster. It's like wow it only take that little bit of time, I'm going to get that. You know, 10 seconds just like that. That's a good test to have.

What about people who aren't self motivated, how do we get them to test?

I would say reach out to people that they being around the most, like family. Their partners. Like that. Tell their partners. If you got somebody, both of you go get tested. You know what I'm saying. Like, you should want to have a good future so both of you should go get tested. And I think having that partner going with them is the best motivation because they be right there with somebody. If you know like, they find out they do have it, that person could like comfort them. You know what I'm saying, they can still go on with that. That's the best thing.

How do we get people to get tested who don't normally do bloodwork, see the doctor, things like that?

I think it should be more billboards. People driving they have a tendency to daze off and have more billboards and stuff like that. And more things that says in big bold letters this is your life, you know, go get the test. Put it on bus stops everywhere. You should put it up so people can see it, because if you have less advertisement, people forget about it. So I think more advertisement is good too.

Mandatory testing. Connecticut and pregnant women example.

I think they should have it here too in Pennsylvania. That should be mandatory for pregnant women because why give birth to a child that's going to live with HIV? You know, that's like...it's not fair to the child. It's not. You know, giving birth to HIV positive child is not...is not fair. So I think the women should get tested.

What about everyone else?

Um far as...even their spouse. Even the person they're with should get it too, you know what I'm saying. Because um, before the woman gets pregnant, she should get the test done anyway with her spouse that way she'll know if she's going to have an HIV infected baby. So I think they both should get the test, man and woman.

What about people not married, not planning on having children?

Yeah people who just dating each other they should get the test too, because that way you know they could find out that they both don't have it, then they could go, you know, a day without using condoms and feel more free with their life, you know. I think that's good too.

What about making people test? How do you feel about that? Interferes with civil liberties?

In a way I kinda think it does, making them go get it. Because you know...It's like...kinda like telling them do it or else. It's like...that's like, some people don't have good coping with that, you know, being told what to do. So it's like...but it would...I really do...I just think they should just put it out there. Like you need to test because it's very important. You know you got so many people getting it around America it's ridiculous, how many people having this thing. It's so costly too. You know, I don't even know when they're going to come out with a cure. I'll be glad when they do because I'll be the first one in line to get it. Yeah, because I'd definitely want to get rid of this thing. It's really been a monkey on my back. Um, waking up knowing damn I got to take this pill again, it's just man...going to the doctor's every month. It's a lot. It really is.

Barrier to people getting tested? Why aren't people getting tested, keeping them from wanting to get tested?

I think it's laziness. It's being lazy with your health. You're being lazy because um you got free clinics all over the place. You got doctor's office all over the place. There's more health things in, you know, in this city than I've ever seen in my life. Like it's laziness, that's what it is.

And why are people lazy with their health?

Because, um, like majority of the people they don't want to take...have good health. You know what I'm saying, they don't want to cut things out of their diet or in their life, or whatever else. They don't want to make a change. They always comfortable with the way they're living. You know. They don't want to make that change. It's like getting off of drugs or something like that. They don't want to make that change.

How relates to testing?

Um, it's the fact that well why should I go get it, I know I didn't have it the first time. You know what I'm saying. They're always saying well I know I don't got it now, so I don't need that test. That's how they...that's how they...I hear people say that. Um, what do I need the test for, you know what I'm saying? I know I didn't have it the first time. But who knows if that person could have went out and cheated on you and now you got it. You wouldn't know that without taking the test. so I think they should get it every 6 months just to make sure.

Out of all the three testing models, which one will get the most people to test?

I think the opt-out will get the most um, the mandatory won't get the most because like I said people don't want to make...don't want to do things that they don't want to do. When they go to their doctors, I think their doctor should slip it in there, um, do you want to get tested for HIV today, and kinda put it out there. I think they'd take it.

What about people who don't go to doctors regularly?

Well, like...like...people wait for mail every day. You know, postage. So slip a card in there, you know in their mail. Like, HIV testing going on here at this center so and so, they're having an HIV awareness carnival, festival something like that. It's going to be like this, going to get free things, free condoms. People like free condoms, they like free stuff like that, they do. Just to have it. I think they should have more festivities with that. People will come out, they'll come out.

So more awareness of resources and things like that?

Yeah, yeah.

So opt-out will be best just by having doctor initiate it? What is it about the doctor initiating HIV testing that makes it more receptive?

Um I think it's best because some people like having their personal physician. People see a lotta uh you know private doctors and stuff like that, and they feel more closer to their family doctors. You know, and having their family doctor tell them you know I think the test is good, that you get the test today. You know if it was better coming from a doctor than from some kinda like free clinic or some person who's like a, uh you know, average person, average physician. I think the doctor should put it out there a lot because I think they play a major role in their lives.

So someone that they feel close to.

Yeah, comfortable. Like a family physician.

Just to summarize, make sure I got everything correctly. So you feel that we need to keep the prevention counseling.

Yeah keep the counseling, because some people do need the comfort.

And a lot of this is just people need to be more proactive about their health.

Yeah

Incentivized not as effective as opt-out?

Yeah, not as effective.

No additional questions/comments.

Demographics

25, male, black, public insurance, high school graduate, annual family income between \$20,000-\$50,000, unemployed (student).

Subject #009

Can you tell me a little bit about when you first got tested?

The first time I got tested I was in Florida. Um, it was ah, they was doing a...study, a drug study. I was on drugs. It was a drug study. And I was tested for it, and it came back positive. But I didn't take it serious. I was like, ah...there ain't nothing wrong with me. That was the first time I ever got tested. And then...then, that went on for years. Knowing, but not doing nothing about it. Okay. And then, the study...another study came up and it was people who was HIV positive. And I went and did that study. That's when I really came to grip that I was HIV positive. But I still didn't do nothing about it. I didn't take no medication, I didn't see no doctor. Then I got involved with a guy that was HIV positive. I didn't tell him I was HIV positive, and he didn't tell me he was HIV positive. But I knew that the girl he had just broke up with was HIV positive. So...kinda knew that he was HIV positive too. But um, he died. He died, from um TB and HIV. But I just recently got out of TB hospital. I did 6 months in the TB hospital. I had tuberculosis and HIV at the same time and pneumonia. PCP pneumonia, PC whatever it is. Yeah, I was in 6 months for that. But that's when I started taking medication. That was in uh June of 2008. I started taking Atripla. That's when I actually came to grips that I was really HIV positive when I got TB. Took a toll on me.

So about how long did that take from when you tested positive to getting treatment and coming to grips?

8 years, yup.

So what motivated you to get into these studies?

Well money because I was on drugs and they was talking about paying me. And that's what I did. I did the study just to get the money. That's when I was doing..that was back in Florida. You know, I did it because I wanted to get high. But I ain't living like that no more. I'm gonna do studies now for money to keep food on my table and keep you know. Not for the use of drugs. But it took me to get TB for me to realize that HIV was as serious as it was you know I mean, because TB is very serious. I mean I was...I was sick as...I went down to 90 pounds. I was sick I couldn't even hold my head up. I was really sick. But thanks to God, you know what I mean he restored my life. I'm back to normal. Not normal I'm still HIV positive, but I overcame the TB. And I was in the hospital and I see these three, four people die when I was in there. So I know I'm lucky to be alive.

So being in the hospital

Yeah, how serious to your health, and how easy it is to be here today and gone tomorrow. All behind neglecting your personal...your...your health. To me today it's serious. Yeah. When they say doctor, at One time I wouldn't go to no doctors, I wouldn't do nothing . but now doctor's appointment, I'm going to make my doctor's appointment. Trying to get my mouth fixed. I ain't care about none of that. I was getting high, I didn't care. I gave up. But I care today.

Before you got that realization, why did you not decide to get treatment?

Because I didn't care. I just didn't care. All I thought about was getting high. That's all that was important. Just getting high. That's what I lived to do, to get high. For years.

That test was related to drug study?

Yup

Tested again?

Yeah, but...I didn't even. That was back when you had to go back for the results. I never went back for the results cause I didn't care. Once they gave me the test and paid me I ain't care what they did . I ain't even want to know. Once I got paid I ain't care, for real ,you know. Yeah.

When got tested during the drug study, any pretest counseling like what it mean to take the HIV test?

Mmmhmmm. Yeah, but I didn't hear none of that. I didn't want to hear that I just wanted them to hurry up and finish and pay me so I could get outta there so I could get high.

So you didn't feel it was beneficial?

Nope, nope. It was beneficial the money. But what they had to say, I couldn't... I don't know nothing about what they said because it wasn't important. Well they probably did. I'm not going to say they didn't, but I don't even remember that part.

Changes in testing recommendations.

Well, to me it's good that the person has...well to me it's better now than it was. Because all that paperwork really will make a person not want to be involved with it. But when I first got involved I did do a lot of paperwork. But I noticed that like around the time when I got sick in 08 from the TB, and then I did HIV testing, I didn't have to go through all that. I do remember the doctor just asking me could he test me for HIV when I got the TB. Yup, and I think it's better that way.

Why paperwork make not want to test?

Because just reading, just having to go through all that. The realization's setting in, you know what I mean. Plus if you already know you're positive or if you know you was having risky behaviors out there and you know. You know what I mean. Deep down in your mind you know. Cause even before I was tested, I knew. I had no signs of it, but I knew that the lifestyle I was living, I knew. and in Florida, it's overpopulation of HIV. Now, I'm telling you at least 8 out of 10 people walking on the streets is HIV positive in Miami Florida. That's where I just came. It's spreading, it's bad. In Miami Florida it's bad.

Here in Philadelphia it's bad too. Article in Inquirer, Philadelphia 5x national average of new HIV infections.

Wow, and you know when I left here, I left here in 96. I left Philadelphia in 96 and went to Florida, HIV wasn't even like it is now. You heard of it but you didn't really know about it. But when I went to Florida it was like wow. You know, just HIV thing, and everybody. I mean, the way I found out was by getting it. I knew I had it but I didn't want to believe it. It's like when I got TB and I was sick with TB. I didn't want to believe it. I could go around oh nothing wrong with me. Until I got to the point I was so sick I couldn't walk. So that made me know.

Okay to verbally say enough?

Yup.

Will that get more people to test?

Yeah, yeah.

Why will more

Because that paperwork is aggravating, frustrating. That's why. [laughs] frustrating. Paperwork. You know what I mean. I think it should be mandatory though. I think it should be mandatory. I think that it's mandatory for everybody even if you ain't risky behavior everybody out there. Because everybody going to say they not or they not doing. Nobody gonna want to say well yeah, I'm actually. And you don't never know what you're partner's doing. He could seem like the most innocent person in the world. You don't never know what they doing. That's why I'm at the doctor's here today. All behind the guy I'm with. They, his doctor called him and tell him that he tested positive for syphilis. Now if you only been with me for a year, where you get syphilis from. I mean Come on. You know, but I'm thinking you an innocent person you know, you ain't messing with nobody but you gotta be doing something. You don't just pop up in your system like that. I ain't crazy, you know. So it's like I think it should be mandatory. I think it should be mandatory. Mandatory. Every 6 months everybody take a blood test. I don't care who you is, you know what I mean. Take a blood test to make sure. Because that's people...that's how it spread. Not knowing. But then in my case not knowing, I ain't care. But today I care. You know. But yup, I think it should be mandatory no matter what, you know what I mean. You go get...people gotta...like I said, it's mandatory but it's not really mandatory, but it's important that people go get tested for cancer and all that, it needs to be mandatory that you be tested for HIV because it's serious and I believe that.

Interfere with rights to choose?

Well yeah, because a lotta people don't...they not going to chose that. Because They don't wanna...like at one time with me I didn't want to know that. I didn't want to know that. But it's good to know because if you take care of yourself you can live a long time.

So knowing help take care of self

Yeah knowing. Because I mean I knew it, but when you on drugs you don't care about nothing but getting high. So I knew it, but it took me to get clean to know that I could live a long time with HIV instead of you know. At first I gave up, at first I ain't care. I ain't care about nothing. But today I care.

Why are people not getting tested?

Uh, they don't want to deal with realization. They don't want to come to grips with that's what it is.

What is it about coming to grips with this that's so difficult?

Well, with...right now today for me it's not. But lots of time, lots of people...not everybody that has it is on drugs. But the majority of people that's HIV positive has drug history, prostituting, you know what I mean. stuff like that.

So not wanting to know is keeping people from testing.

Yeah not wanting to know, not wanting to deal with it. But then if you...I found out not dealing with it made it worse. Because then you infecting people that's innocent that's got nothing to do with it but you got it, you know. And it's not fair. If I had the chance to do it all over again when I first found out, I would have done different, you know what I mean because I really didn't care, but I care today. I wouldn't put nobody under, in no danger because of what I have, you know. But it took a lot for me to get to that point.

Incentivized.

Yup, yup. Because that's what started me on wanting to be HIV...if somebody...I call it taking a bribe. Somebody bribe me. If you do this I'll give you that, okay. Yeah that works. It really do. It worked.

Specific type of thing we can give people?

Like vouchers for eating, food places, money, and uh movie tickets and stuff like that. Any you know, anything where they feel like they getting paid to do what they doing, you know.

Any specific dollar amount?

No, no just something for they time. Just something, they be happy with it. You know some people don't have any kind of income and \$5 make them happy. You know something. Feed them, give them a meal. Tell them here's a McDonalds gift certificate, go eat 5 dollars worth of McDonalds come you know, take an HIV test. See that's how they did it in Florida. In Florida, it's always you know, they always, it was always bribery to get an HIV test. They paid you good in Florida. Yeah, I was going to ah, a lot of them studies. I was going to a women's support, HIV. I went once a week for five weeks, and every visit I got \$25. And then they, when you went there they fed you while you were waiting. And all you did was answer questions. You know, surveys, once a week. Then after five weeks you went once every three months. Until then you get done to once a...after a year....well not a year but after 6 months it was over with. But you know what I'm saying over that course of time I had made about \$300. I knew every week on Thursday I knew I had to go there. I was getting high then. And that was like wow, \$25. It ain't nothing to me now, but then it was big. In Florida they do it. HIV is...wow. I was there, I seen so many people die from that. I had people I was friends with I lived with that died. At least four people died from HIV. I don't want to die from it. If I'm going to die, I want to die from old age. I don't want to die from HIV. I mean I know I might. But I believe that if I take care of myself I can live. And I choose to take care of myself. Today. Now about a year ago, I ain't care, you know. I ain't care about nothing.

How get people to want to take care of self?

That's a good question. To me, it took a tragedy for me to want to take care of myself. It took me getting, TB, HIV, PCP pneumonia and all that stuff all together, and to be hospitalized with tubes hanging all out for me to realize. I don't know what's going to take the next man, but that's what it took for me. I don't know what it take for them. Might not take as much tragedy as it did for me to care, to realize. That's what stopped me from using drugs and all that. And I have children and grandchildren. I was away from my family from 96..well really from 95 till about...December of 08. Yup. On drugs. And all in the state of Florida where I had no family. Just out there on drugs, living in the streets. That's how I got HIV. And my family don't know it. I haven't told my family. In due time I tell them. I ain't in no rush to tell them. They'll find out eventually.

Between the three models, which one will work best?

Incentive, paying them to do it, okay really. Mandatory, see you got people out here that you can't make...it's like they fight against anything that's mandatory, you understand what I'm saying. That's how I was. You couldn't tell me I had to do nothing. Who could they do it, you know? You must gonna lock me up and do it because that's the only way you gonna do it. If you ain't locking me up and putting that drug, making me do it, actually taking me there and getting it done, I ain't gonna do it. If I leave my job and say I'll be back by Monday to do it, I ain't coming back. Better lock me up and put me to jail by Monday and take me there to do it and then let me go. I ain't like that now, but I was.

So incentivized best?

Yup, bribing them.

Any other way?

Nope. Just either bribery, or...well I don't believe mandatory is going to work. I think it should be mandatory, but I don't think it's going to work. But it should be. But I don't think it's going to work.

So just because it's hard to make people do stuff.

Yeah because that's something you really don't want to know but you need to know. But you really don't want to know. You don't want nobody to tell you have HIV or you have AIDS and you only got so much time to live or you know what I mean. Or you start taking medication and they start telling you...all the meds...you done got so bad that the medication can't cure you. And you know what I mean, you don't want to hear that. Noo.

Any additional questions/comments?

No.

41, female, African American, SSI, public insurance, 12th grade (did not graduate), unemployed.

Subject #010*Circumstances around when first tested*

When I first was tested, uh, it happened uh, the first, uh how can I say this. It took me by surprise. I had pneumonia and I thought it was a cold, but I found out I had pneumonia. And the instance when I was admitted to the hospital when they did bloodwork and it came back and that's how I found out that I was HIV positive.

So it was physical health problem but you just wanted to check up on that.

Yes

When they tested you was it anonymous or confidential?

It was a confidential test. which I...at that time I didn't know if I had asked for it or...I was in so much distress that they tried everything. I had a spinal tap and I mean I was actually balled up I couldn't even walk I was so sick. And I think that...I don't know if it was voluntary or not but that's what they came back with my bloodwork and they told me.

Pretest counseling where they told you what it meant to take test?

No, not at that time. This was back in I would say...89 or 90. 1989 or 90, and things were fairly new. I was totally out of it after that.

How feel?

Made me feel scared and I was depressed and...didn't know what to do. Didn't know what to do.

How long come to grips with diagnosis?

Over the years, at the time 89-90 or 92, I looked...I put it in the back of my mind, I didn't seek any help. I just started coming here um...last year. Last February. And the doctors that I've talked with are amazed that I wasn't hospitalized or anything since then. I might have had a cold that was really bad or anything. But I would try to keep up on taking, getting medicine to get that out of me. And I knew how pneumonia felt so I knew exactly if I needed...if it got that bad to go to the hospital.

How many years?

I would say about...at least about 14 to 15 years. Yes.

When got tested, it was just part of workup for pneumonia?

They didn't explain anything about the test. I was told when I was released from the hospital if I'm remembering correctly was to come back to this clinic, you know, well at the time it was women's medical that's where I was going to the hospital and being seen. Um, and I went back and I just think I got scared. One time I think I had them draw blood and I never came back, I just never came back again as far as seeing anything about my blood or anything.

Why never came back and put it at back of mind?

I was just scared, scared to death of dying. At that time when people were, there wasn't really too much out here to help people live long and I had a few friends that passed away from it. Um, in the meantime I got married and you know at the time, scared too. I had children already, and they're fine. They're fine.

Fear of what it meant to be positive?

Yes fear and association with it, of family and friends and stigma which you see.

Opt-out testing. Changes in CDC testing recommendations. Aware of changes?

No, no.

What do you think of these changes?

I think those changes are great. I think that's great. Uh, I think it's a good thing, it's a good thing. It...without the paperwork because if that's on the back of your mind where you wondering, you're wondering if you have some kind of thought, that you think you...that you want to find out your status. This way, with signing all the paperwork it can hinder it. That's what I'm...that's how I'm looking at it. Where this way if it's verbally, you know, you can just say go ahead on, go and test me for everything.

What is it about the paperwork that makes it a hindrance?

For a person that don't, that doesn't know, that's not aware of the...infection itself, it can be um just overwhelming. That's what I think, overwhelming.

Overwhelming as in too much paperwork or too much information?

The paperwork, yeah the overwhelming and when there's so much paperwork, and mentally...well I'm talking about me, mentally as far as do I really want to know, or I'm scared, and I'm hoping and I'm hoping that I'm not, and the anxiety of it all.

So the paperwork makes it all sink in, and makes you anxious?

Yes, yes.

So do you think verbally saying okay is enough consent.

I think that, that's, more than enough. I think that's a great thing.

What about taking away pretest prevention counseling?

You said that happened, they took that away?

Yeah, before you take the test, you don't need to do the pretest information.

Oh okay. I'm not so sure about that. Because uh, if my memory is correct, I don't think, everything was so overwhelming to me that if they did do that with me, I didn't...I wasn't... it just went in one ear and out the other. Not that I...I knew what the circumstances, and I was smart enough to know about HIV at the time. But, for a person their first time, it can be really overwhelming like that. And that's, just about that.

Prevention counseling help reduce some of the overwhelmingness?

You know I think it could be helpful. It could be helpful. Either before or after. Before or after. Or maybe after you have the test, and then when you come back for your results and someone could be there to explain things to you.

Opt-out help increase number tested?

Yes, I do.

Why?

I think because where...it's just...okay say I could just...if I could just come in and get a swab or whatever and just be anonymous without having to be sitting somewhere and being seen you know

so much. And uh, nervous. And it's much quicker where you won't have as much on your mind. That's the way I look at it.

So reducing the time from where you get in there and take the test?

Yes that's what I'm trying to say, yes.

Incentivized testing, giving movie ticket or money to come in to take a test.

I think that's...that's good too. I think that's good too. Uh, I know if uh, well now the way I feel now, but if someone offered say well okay here, here's...I'll just say dinner for two or a gift card for \$10, I think that would spark my interest enough to go ahead and see about my health. See where I stand.

Why do you feel it will require giving something to spark someone's interest?

Well in these economic times things are really, really tough right now but that's beside the point. Some people, well some people that's the way...getting something for something. Um...not that I would be like that, but it would be...in my mind right now, maybe if they had something like that then, maybe I would have been a little more at ease with uh, continuing and seeing about my health. It took a lot for me to come here now. It took me a lot to come, what I'm getting done, the counseling that I'm receiving and the doctors that I'm seeing. I really appreciate it, It took just took a long time for me to come to terms with what's going on with me.

What did it take to come to terms with everything.

Uh meeting someone that's a good friend of mine, and he wasn't ashamed of his status and I never was able to talk to anyone about that. Anyone um, I mean anyone. And he encouraged me to come, to see, to go see about myself. And from then on I've just been running with it and because I have...I have a family and I want to be around for them.

So gave you inspiration in a sense?

Yes, yes.

Going back to incentivized, do you think that will increase number people to test?

Yeah, I think so. I think that's one way of, that's a nice way of putting another little wrench in it, however you want to say. [laughs] Yes, you know, all kinds of different ways to get people to test, get tested.

Particular type of gift that's most encouraging?

Well let's see...I mean...It's a shame for your health about monetary, you know...maybe some kind of...for people that their healthcare is not up or they need help with their healthcare. Maybe some kind of free visit or something like that. Some kind of free visit, or uh one bloodscreening or some kind of test that can be free of charge if they're on certain kinds of insurance. Maybe a free dental exam, which a lot of insurances don't cover that. That's a problem.

What about those who don't have problems with insurance? What kind of incentive to encourage them?

I would say uh, I've seen it in the last couple of years myself, um, just being out there advertising...advertising. Flyers uh public service announcements, uh that's where I see. That's the way I see it. Like that. That's what I see. Awareness or however you want to put it. More awareness. Even though it's out here, from the time that this epidemic started, uh things kind of weaned off lately. From where I see it, things kind of weaned off because of the strides that the medical world

has made, you know. And keeping people alive, and keeping things in check. Keeping things in check. So it's not like the forefront anymore where I wish they would, I wish they would find a cure or some kind of vaccine or something. Not to forget about it. People are living longer...personally, beside medication, if they are taking medication, but I think the will to live and to have some kind of...the will. I think that's what kept me going. And they were amazed...my doctors were amazed to see that I wasn't in nobody's care when I came here and in no one's care all that time.

I know you had mentioned something about monetary not being too good, giving them \$5 or things like that.

Yeah, you know, I... I think if it took that, yes, yes \$5 why not. Because I think that, yes...monetary incentive, yes. Why not, why not. If not monetary then some kind of service that the healthcare provider can provide, you know. Maybe a free lunch.

What about movie tickets?

Yes, yes I do. I think they would be encouraging.

Anything that would be most encouraging?

I would say the movie tickets. Movie tickets.

Why?

Um because that would give, that would give you and someone else or whoever a chance at a night out to get away from everything. And with that being expensive as it is these days too. It's just better to wait until it comes out on DVD, burn the DVD and sit at home and watch it. It's just so expensive now. And to take a date, you know you want to take a date, you almost have to mortgage the house to go to the movies these days.

Mandatory testing. Connecticut and pregnant women example, testing prisoners.

Hmm. Wow. I never thought about that. Hmm. Long as it's confidential. Concerning prison, as long as that confidentiality stays intact, I have no problem with that. Because uh, I mean that's the last place where you wind up and...and...everyone knows your status. You know, if a prisoner, they could use it against you or just stay away from you because of the stigma, people don't know that it's, you know, that a lot of people have it.

What about general population?

Well everyone thinks different. Once I found out, I was responsible anyways, but that's a hard one. I'm not sure. I'm not sure. Mandatory....yes as long as it's confidential. Hmmm.

Like if it were anonymous?

Yeah, that's the word. Like if it was a job interview that you had to get an HIV test. Or...or...say if you wanted health insurance, if that was a way for them to turn you down, I don't know....no...no. I'm not for it in all realms. I'm not. Because yeah, as a matter of fact, I had some problems getting insurance because I was HIV positive. And I really didn't appreciate that. I didn't get tested through them, I was just honest and said something. And then I was turned down.

What if it were completely confidential and only you knew your status, do you think mandatory would help?

Oh yes. Yeah.

If we were in a perfect world, and it was completely confidential, it would help?

Oh yes, I do believe that.

What about right to choose?

Oh wow. When you think of it like that...okay maybe I put it like this. Mandatory with the option of opting out. Well...that's like an oxymoron right there...that's really deep. I'm not sure, I'm not sure when I think about it like that because mandatory's mandatory.

Ideas of potential ways to make it mandatory. Link with tax form, don't know status, just give number that shows have taken a test.

Never knowing the person per se, but just a number. Well, I don't think I would have a problem with that. Because I think that the person has the right to, when they find out, to pursue their treatment. If it's just for statistics you know and the world to see how many people are suffering from this, I think it's a good thing. I don't know of another way.

The idea of confidentiality, keeping information confidential.

Yeah, that's my...that's my main concern.

Any one model most effective in getting most people to test? Opt-out, incentivized, or mandatory?

I uh...I think it would be...just to go back to opt-out, hit me again with what that is?

Can verbally agree to take test, no more paperwork,

I'm for the opt-out, and the incentive. The incentive. If that's a way of getting more people to test. and young people. A lot of young people. And old people. Everybody.

Biggest reason why people not testing?

I feel...with...like I said earlier, with the stigma with HIV and how it's not prevalent so much in the news anymore or the print media, or in the news. It just took a little backseat. It's not as prevalent. It's here, but it's not as prevalent. You don't hear as many things about it anymore out in the media. And then people that do read seen that there are a lot of medication out here these days, different treatments that people get and they're living longer and it's rare, well it's not rare, but people are not at least what I think are not succumbing to this as much as they were in years past you know. I hope I answered that question.

So you're saying that it's stigma, and the idea that awareness is not as high as used to be?

Yeah that's what I think. When the awareness was really high, I was really trying not to hear it at the time. I mean I was listening, I knew but I was really trying to blocking it out of my mind. I've seen public service announcements. But I think it could be some more. Yeah, more.

Any other way that could work to encourage people to test?

Hmm. You know, well I don't know if this is too deep but uh, maybe with...counseling, family counseling, ah uh with other issues where it comes up in counseling. Say if someone had a child a parent or something and they had to go to counseling, where maybe this could be a question to ask also, just slip it in there to, slip it in there while they have the family together or whoever it may be, mother to child, son and daughter, and the father or whatever. I think that would be, that's the way I would see something helping a little bit.

Why connect it with family counseling?

Because I think that uh as much as we'd like to say that we talk to our children and uh, we assume, a lot of people assume that they know what's going on out here, but they really don't. I mean we really don't, and grown people too. You know, that maybe by being in that setting, it would be easier to talk about and with having your loved ones there.

So support system.

Yes, correct. Yes.

Anything else that's come up to mind, questions or comments?

I do want to say this. I really appreciate this organization here, it's a really good place. Um, I've never felt more comfortable coming to, I don't think if it was somewhere else, I don't think I'd be able to, not to say I'd not be able to go but I don't think I'd be comfortable. The staff here is really tremendous. I feel...I feel my privacy is protected, everything is protected, and you're treated with dignity. Really...really, that's why I feel really good about coming here to this program. And the people are really great from the front to the back.

Patient demographics

45, male, black, associate's degree, unemployed, less than \$20,000, public insurance

APPENDIX F: IRB CONSENT FORM

Version: February 10, 2009

Page 1 of 6

Drexel University Consent to Take Part in a Research Study

1. **SUBJECT NAME:** _____
2. **TITLE OF RESEARCH:** Understanding HIV Positive and Negative Patients' Perspectives on Opt-Out, Incentivized & Mandatory HIV Testing
3. **INVESTIGATOR'S NAME:** Dr. Nicole Vaughn
4. **RESEARCH ENTITY:** Drexel University
5. **CONSENTING FOR THE RESEARCH STUDY:** This is a long and an important document. If you sign it, you will be authorizing Drexel University and its researchers to perform research studies on you. You should take your time and carefully read it. You can also take a copy of this consent form to discuss it with your family member, physician, attorney or anyone else you would like before you sign it. Do not sign it unless you are comfortable in participating in this study.
6. **YOUR RIGHT TO PRIVACY AND CONFIDENTIALITY:** Very specific information on your right to privacy and the confidentiality of the use and disclosure of your personal health information can be found at the end of this consent form. We need your authorization to use and disclose the health information that we may collect about you during this research study. *To be in this research study you must read and sign the authorization at the end of this consent form.*
7. **PURPOSE OF RESEARCH**
You are being asked to participate in a research study. The purpose of this study is to assess HIV negative and HIV positive patients' opinions towards opt-out, incentivized, and mandatory HIV testing. Opt-out testing is where the patient is told that an HIV test will be performed and the doctor assumes that the patient agrees to take the test unless the patient specifically declines. Incentivized testing is where patients are given a reward, such as a free movie ticket, for taking an HIV test. Mandatory testing is where patients are required to take the test and do not have the option to refuse. The interview results will inform us what can be done to improve HIV testing rates in the U.S. This research project is conducted as partial requirement by one of the researchers to obtain a Master's of Public Health degree from Drexel University's School of Public Health.

APPROVED
Office of Regulatory Research
Compliance
Protocol # 1007-01P
Approval Date: 02/04/2009
Expiration Date: 02/02/2010



Subject Initials: _____

This study is only being conducted at Drexel University, and a total of 20 participants will be recruited into the study. You will be in the study for only one visit.

You have been asked to participate in this study because you satisfy the following eligibility requirements:

- Male or female patient between the ages of 18-64
- Available to speak for approximately 45 minutes

If you do not satisfy these requirements, you will not be able to participate in this study. *Please note that a positive HIV test result is not required to be included in this study. Any prior treatment or medication should not affect your risks or benefits for taking part in this study.*

8. PROCEDURES AND DURATION:

All procedures are experimental. You understand that the following things will be done to you:

During your one-time visit, you will be asked questions about:

- Your HIV testing history
- Your feelings regarding opt-out, incentivized, and mandatory testing
- What you feel could be done to improve HIV testing rates in the U.S.

Your responses will be audio taped. The interview will take approximately 45 minutes to complete.

9. RISKS AND DISCOMFORTS/CONSTRAINTS:

There are few risks associated with being in this study. You may experience some emotional discomfort when discussing your HIV testing history, and your feelings regarding the different types of HIV testing. Possible loss of confidentiality is another potential risk encountered during this study.

10. UNFORESEEN RISKS: Participating in this study may involve unforeseen risks. If any unforeseen risks occur, they will be reported to the Office of Regulatory Research Compliance.

11. BENEFITS: There will be no direct benefits to you from participating in this study.

12. ALTERNATIVE PROCEDURES: The alternative is to not participate in this study.

13. VOLUNTARY PARTICIPATION:

APPROVED
Office of Regulatory Research
Compliance
Protocol # 10007-01P
Approval Date: 02/04/2009
Expiration Date: 02/03/2011



Subject Initials: _____

You understand that being in this study is voluntary. Your health care will not be affected in any way if you decline to be in or later withdraw from this study. There will be no cost to you.

14. STIPEND/REIMBURSEMENT:

After completing the interview, you will receive \$10 for your time.

15. RESPONSIBILITY FOR COST:

There are no costs associated with participating in this study.

16. IN CASE OF INJURY:

Treatment for Injury

If you have any questions or believe you have been injured in any way by being in this research study, you should contact Dr. Nicole Vaughn at telephone number 215-762-7547. However, neither the investigator nor Drexel University will make payment for injury, illness, or other loss resulting from your being in this research project. If you are injured by this research activity, medical care including hospitalization is available, but may result in costs to you or your insurance company because the University does not agree to pay for such costs. If you are injured or have an adverse reaction, you should also contact the Office of Regulatory Research Compliance at 215-255-7857.

17. CONFIDENTIALITY AND PRIVACY:

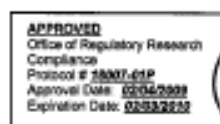
This section gives more specific information about the privacy and confidentiality of your health information. It explains what health information about you will be collected during this research study and who may use, give out and receive your health information. It also describes your right to inspect your medical records and how you can revoke this authorization after you sign it.

By signing this form, you agree that your health information may be used and disclosed during this research study. Your health information may be disclosed or transmitted electronically. We will only collect information that is needed for the research study. Your health information will only be used and given out as explained in this consent form or as permitted by law.

In any publication or presentation of research results, your identity will be kept confidential.

A. Individually Identifiable Health Information That Will Be Collected

The following personal health information about you will be collected and used during the research study and may be given out to others:



Subject Initials: _____

- Your name, date of birth;
- Personal medical history;
- Information learned during surveys done as part of this research study

B. Who Will See and Use Your Health Information Within Drexel University

The research study investigator and other authorized individuals involved in the research study at Drexel will see your health information and may give out your health information during the research study. These include the research investigator and the research staff, the institutional review board and their staff, legal counsel, research office and compliance staff, officers of the organization and other people who need to see the information in order to conduct the research study or make sure it is being done properly.

C. Who Else May See and Use Your Health Information

Other persons and organizations outside of Drexel University may see and use your health information during this research study. These include:

- Governmental entities that have the right to see or review your health information, such as the Office of Human Research Protections.

If your health information is given to someone not required by law to keep it confidential, then that information may no longer be protected, and may be used or given out without your permission.

D. Why Your Health information Will Be Used and Given Out

Your health information will be used and given out to carry out the research study and to evaluate the results of the study.

E. If You Do Not Want To Give Authorization To Use Your Health Information

You do not have to give your authorization to use or give out your health information. However, if you do not give authorization, you cannot participate in this research study.

F. How To Cancel Your Authorization

At any time you may cancel your authorization to allow your health information to be used or given out by sending a written notice to the Office of Regulatory Research Compliance, 1601 Cherry Street, 3 Parkway Bldg., Mail Stop 10-444, Philadelphia, Pennsylvania, 19102. If you leave this research study, no new health information about you will be gathered after you leave. However,

APPROVED
Office of Regulatory Research
Compliance
Protocol # 18667-01P
Approval Date: 02/04/2009
Expiration Date: 02/03/2012



Subject Initials: _____

information gathered before that date may be used or given out if it is needed for the research study or any follow-up.

G. When Your Authorization Ends

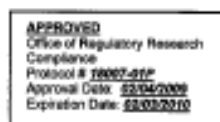
Your authorization to use and give out health information will continue until you withdraw or cancel your authorization.

H. Your Right To Inspect Your Medical and Research Records

You have the right to look at your medical records at any time during this research study. However, the investigator does not have to release research information to you if it is not part of your medical record.

18. OTHER CONSIDERATIONS:

If you wish further information regarding your rights as a research subject or if you have problems with a research-related injury, for medical problems please contact the Institution's Office of Regulatory Research Compliance by telephoning 215-255-7857.



Subject Initials: _____

19. CONSENT

- I have been informed of the reasons for this study.
- I have had the study explained to me.
- I have had all of my questions answered.
- I have carefully read this consent form, have initialed each page, and have received a signed copy.
- I authorize the use and disclosure of my personal health information as explained in this consent form.
- I give consent voluntarily.

DO NOT SIGN THIS INFORMED
 CONSENT AFTER THIS DATE 02-03-10

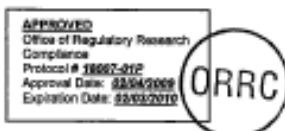
 Subject or Legally Authorized Representative

 Date

 Investigator or Individual Obtaining this Consent/Permission

 Date
List of Individuals Authorized to Obtain Consent/Permission

<u>Name</u>	<u>Title</u>	<u>Day Phone</u>	<u>24 Hr Phone #</u>
Nicole Vaughn	Ph.D.	215-762-7547	215-762-7547
Hans P Schlecht	MD	215-762-6794	215-762-6794
Sirena Sun	BS	240-274-7527	240-274-7527



Subject Initials: _____

